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Health State Descriptions for Canadians

Health State Descriptions for Canadians: Cancers

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This document is one of a series that covers the major disease groupings that affect Canadians. The series is primarily intended to document the disease classifications used in the Population Health Impact of Disease in Canada (PHI) research program and help researchers to understand how the PHI estimates were calculated. It is also of interest to health professionals, advocacy groups, and individual Canadians who are looking for an overview of how living with cancer affects day-to-day functioning throughout its various stages of progression and treatment.

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Note of appreciation

Canada owes the success of its statistical system to a long-standing partnership between Statistics Canada, the citizens of Canada, its businesses, governments and other institutions. Accurate and timely statistical information could not be produced without their continued cooperation and goodwill.

Context: Health state descriptions for Canadians

This document provides standardized descriptions for the main health states associated with the progression and treatment of a disease. These descriptions are the first step in measuring how living with a disease and its treatment affects health-related quality of life in terms of physical, mental, and social well-being.

Underlying this approach is a new tool to measure functional health. Among other attributes, pain, limitations to physical functioning, or anxiety can limit an individual's ability to participate in day-to-day activities. We use the Classification and Measurement System of Functional Health (CLAMES), with eleven such attributes that span physical, social and mental well-being. For each of these, there are four or five levels ranging in severity from no limitations in the attribute to severe limitations. Level 1, for instance, represents no limitations; for the attribute describing pain and discomfort it would read "generally free of pain and discomfort." Table 1 shows the complete list of levels for each attribute.

For each health state from initial diagnosis to remission or palliation, we describe a "typical" case based on literature review and clinical experience. Although each individual will have a unique experience, these general descriptions are needed to measure health at the population level.

These descriptions were used to elicit preference scores from panels of Canadians based on techniques grounded in utility theory. Preference scores, which indicate the relative preference for a health state compared with full health, help us understand how Canadians view the various aspects of functional health. Along with data on incidence and duration, preference scores contribute to estimates of the impact on the Canadian population of both disease and risk factors that contribute to them.

Measured in terms of years of life lost and year-equivalents of reduced functioning due to the disease these estimates allow us to determine how many years of life—and how many years of healthy living—are lost due to specific diseases and risk factors. They provide answers to questions such as "what would be the impact of reducing obesity on the health of Canadians?" both in terms of lives saved and in terms of increased health over their lifespan.

This document is one of a series that covers the major disease groupings that affect Canadians. The series is primarily intended to document the disease classifications used in the Population Health Impact of Disease in Canada (PHI) research program and help researchers to understand how the PHI estimates were calculated. It is also of interest to health professionals, advocacy groups, and individual Canadians who are looking for an overview of how living with cancer affects day-to-day functioning throughout its various stages of progression and treatment.

More information on the Population Health Impact of Disease in Canada (PHI) research program and the development of these estimates is available at http://www.phac-aspc.gc.ca/phi-isp/index.html.

Table 1
Classification and Measurement System of Functional Health (CLAMES)

Core attributes

Pain or discomfort

1 Generally free of pain and discomfort
2 Mild pain or discomfort
3 Moderate pain or discomfort
4 Severe pain or discomfort

Physical functioning

1 Generally no limitations in physical functioning
2 Mild limitations in physical functioning
3 Moderate limitations in physical functioning
4 Severe limitations in physical functioning

Emotional state

1 Happy and interested in life
2 Somewhat happy
3 Somewhat unhappy
4 Very unhappy
5 So unhappy that life is not worthwhile

Fatigue

1 Generally no feelings of tiredness, no lack of energy
2 Sometimes feel tired, and have little energy
3 Most of the time feel tired, and have little energy
4 Always feel tired, and have no energy

Memory and thinking

1 Able to remember most things, think clearly and solve day-to-day problems
2 Able to remember most things but have some difficulty when trying to think and solve day-to-day problems
3 Somewhat forgetful, but able to think clearly and solve day-to-day problems
4 Somewhat forgetful, and have some difficulty when trying to think or solve day-to-day problems
5 Very forgetful, and have great difficulty when trying to think or solve day-to-day problems

Social relationships

1 No limitations in the capacity to sustain social relationships
2 Mild limitations in the capacity to sustain social relationships
3 Moderate limitations in the capacity to sustain social relationships
4 Severe limitations in the capacity to sustain social relationships
5 No capacity or unable to relate to other people socially

continued on next page...

Supplementary attributes

Anxiety

1 Generally not anxious
2 Mild levels of anxiety experienced occasionally
3 Moderate levels of anxiety experienced regularly
4 Severe levels of anxiety experienced most of the time

Speech

1 Able to be understood completely when speaking with strangers or friends
2 Able to be understood partially when speaking with strangers but able to be understood completely when speaking with people who know you well
3 Able to be understood partially when speaking with strangers and people who know you well
4 Unable to be understood when speaking to other people

Hearing

1 Able to hear what is said in a group conversation, without a hearing aid, with at least 3 other people
2 Able to hear what is said in a conversation with 1 other person in a quiet room, with or without a hearing aid, but require a hearing aid to hear what is said in a group conversation with at least 3 other people
3 Able to hear what is said in a conversation with 1 other person in a quiet room, with or without a hearing aid, but unable to hear what is said in a group conversation with at least 3 other people
4 Unable to hear what others say, even with a hearing aid

Vision

1 Able to see well enough, with or without glasses or contact lenses, to read ordinary newsprint and recognize a friend on the other side of the street
2 Unable to see well enough, even with glasses or contact lenses, to recognize a friend on the other side of the street but can see well enough to read ordinary newsprint
3 Unable to see well enough, even with glasses or contact lenses, to read ordinary newsprint but can see well enough to recognize a friend on the other side of the street
4 Unable to see well enough, even with glasses or contact lenses, to read ordinary newsprint or to recognize a friend on the other side of the street

Use of hands and fingers

1 No limitations in the use of hands and fingers
2 Limitations in the use of hands and fingers, but do not require special tools or the help of another person
3 Limitations in the use of hands and fingers, independent with special tools and do not require the help of another person
4 Limitations in the use of hands and fingers, require the help of another person for some tasks
5 Limitations in the use of hands and fingers, require the help of another person for most tasks

Cancers

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Note to reader

How to read the classification:

Health states are classified using eleven attributes, each with 4 or 5 levels. Level 1 indicates no limitations, while level 4 or 5 are the most severe limitations. **Please note that these levels are a shorthand for the classification: they are not measurements on an interval scale.*** A complete list of the attributes and levels appears as Table 1.

As an example, we can look at two health states, the first describing the health state at diagnosis for cancers with very good prognosis and the second describing the health state for a more advanced cancer during the last month of life, during terminal care.

Individuals with early stage breast cancer (a very good prognosis) could be described by the following:

Somewhat unhappy (level 3 of Emotional State)
Mild limitations in the capacity to sustain social relationships (level 2 of Social Relationships)
Moderate levels of anxiety experienced regularly (level 3 of Anxiety)

Core						Supplementary				
1	1	3	1	1	2	3	1	1	1	1

By contrast, the following describes terminal care:

Severe pain or discomfort (level 4 of Pain or Discomfort)
Severe limitations in physical functioning (level 4 of Physical Functioning)
Very unhappy (level 4 of Emotional State)
Always feel tired, and have no energy (level 4 of Fatigue)
Somewhat forgetful, and have some difficulty when trying to think or solve day-to-day problems (level 4 of Memory and Thinking)
Severe limitations in the capacity to sustain social relationships (level 4 of Social Relationships)
Moderate levels of anxiety experienced regularly (level 3 of Anxiety)
Limitations in the use of hands and fingers, require the help of another person for some tasks (level 4 of Use of Hands and Fingers)

This is represented by

Core						Supplementary				
4	4	4	4	4	4	3	1	1	1	4

Classification of the major health states in the progression and treatment of cancer are provided in the Summary table.

* For instance, the difference between level 1 and level 2 is not the same as between level 3 and level 4. In addition, attributes are not equally important in terms of health state preferences. For more information on health state preferences developed from these scores, please see http://www.phac-aspc.gc.ca/phi-isp/index.html.

Summary table:
Classification of health states related to cancer

Health state	Attribute and level: Pain or discomfort	Physical functioning	Emotional state	Fatigue	Memory and thinking	Social relationships	Anxiety	Speech	Hearing	Vision	Use of hands and fingers
At diagnosis											
Prognostic category											
Very good prognosis	1	1	3	1	1	2	3	1	1	1	1
Fairly good prognosis	2	2	3	2	1	2	3	1	1	1	1
Poor prognosis	2	2	3	2	1	3	3	1	1	1	1
Metastatic disease	3	2	4	3	2	3	4	1	1	1	1
Leukemia											
Chronic lymphocytic leukemia	2	2	2	2	1	2	3	1	1	1	1
Childhood acute lymphoblastic leukemia	2	3	3	3	1	3	3	1	1	1	1
Treatment											
Surgery											
Post-operative in-patient	2	3	3	3	1	3	3	1	1	1	1
Post-operative out-patient	2	2	3	2	1	2	3	1	1	1	1
Radiotherapy											
Curative	3	2	3	3	1	2	3	1	1	1	1
Palliative	2	3	4	4	2	4	3	1	1	1	1
Chemotherapy											
Mild toxicity	2	2	3	3	2	3	3	1	1	1	1
Moderate toxicity	2	2	3	3	2	3	3	1	1	1	2
Severe toxicity	2	2	3	3	2	4	3	1	1	1	2
Hormonal therapy	1	2	2	3	2	2	2	1	1	1	1
Post-surgery bone marrow transplantation	3	2	2	2	1	3	3	1	1	1	1
Subsequent health states											
Remission											
After surgery	2	2	2	2	1	3	2	1	1	1	1
After radiotherapy	2	2	2	3	1	2	2	1	1	1	1
After chemotherapy	2	2	2	2	2	2	2	1	1	1	1
After hormonal therapy	1	2	2	3	1	2	2	1	1	1	1
Palliative care	3	3	4	3	2	4	3	1	1	1	3
Terminal care	4	4	4	4	4	4	3	1	1	1	4

Introduction

Cancer cells are characterized by abnormal, uncontrolled and progressive growth. Malignant tumours tend to infiltrate the surrounding tissues and to give rise to distant metastases (spread of disease to other parts of the body away from the primary site).

Most cancers are classified using a staging system based on tumour size, extent of lymph node involvement, and evidence of distant metastasis. Generally, treatment options for early stage cancers (localized disease) are designed to achieve local control. Therapy for more advanced regional cancers aims at local-regional control, with a lower probability of "cure."* Cancers diagnosed at the most advanced stage have already metastasized to other parts of the body and, with a few exceptions, are treated with palliative intent to increase length of survival, maintain quality of life and treat cancer-related symptoms, when curative intent is not possible.

The psychosocial impact of a diagnosis of cancer cannot be underestimated. "Acute psychological distress is to be expected as a patient confronts the implications of cancer: possible death, pain, dependence on others, disability, disfiguring changes in the body, and loss of function, all of which endanger his or her relationships with others."[1] From this description, we can assume that for most cancers, patients experience the emotional impact created by the initial diagnosis, as well as the knowledge that they may have months of therapy ahead of them.

There is likely to be uncertainty and anxiety experienced while the cancer is "in remission," until the individual is "cured" or relapses. Upon relapse, the patient is faced with more diagnostic and therapeutic options and more uncertainty. Patients who are told that there is no longer a way of curing the cancer must come to terms with the finality of their lives and with months of palliation and terminal care.

This document examines the functional limitations—physical, emotional and social—experienced by patients at the time of diagnosis of cancer and as they undergo the most common therapeutic modalities used, such as surgery, radiotherapy, chemotherapy and hormonal therapy (for prostate cancer). The long-term effects of these treatments are also examined, as are the functional limitations related to palliative and terminal care.

The document starts with an overview of progression and treatment for the three most frequently diagnosed cancers in each of three prognostic groups: bladder, breast, prostate (very good prognosis); colorectal, non-Hodgkin's lymphoma, renal (fairly good prognosis); lung, pancreatic, and stomach cancer (poor prognosis). These nine cancers represent almost 72% of all (estimated) cases diagnosed in

* While it is generally acknowledged that cancer patients are not "cured," clinicians approach therapy with curative intent.

2002.[2] Two types of leukemia are also described: chronic lymphocytic leukemia (most common leukemia among adults) and acute lymphoblastic leukemia (most common leukemia among children).

The remaining sections provide descriptions and classifications for health states at diagnosis; while receiving treatment; and while in subsequent health states, including remission, palliation and terminal care. Readers should bear in mind that an individual will progress through various health states.

The cancers

This section provides an overview of the symptoms and usual treatment path for nine cancers frequently diagnosed in Canada. International Classification of Disease (ICD-9) coding is provided for each cancer type. Literature on these cancers was used to develop generic descriptions for three prognostic categories; these descriptions are provided in the next section (page 17). These nine cancers are the three most common cancers in each prognostic category. An overview of two types of leukemia is also provided.

Stomach (gastric) cancer (ICD-9 151)

In 2002, an estimated 1,800 men and 1,000 women were diagnosed with stomach cancer in Canada. The ratio of deaths to new cases was 70%, making this type of cancer the third worst in terms of overall prognosis, after pancreatic and lung cancer. Most cases are diagnosed at an advanced stage, with a high likelihood of spread to adjacent organs, such as the spleen or pancreas. The tumour can also spread directly into the esophagus or the duodenum. In approximately half of the resected cases, invasion into the lymphatic system is seen.

Stomach cancer incidence has been decreasing in North America, although it is considered epidemic in Japan, Eastern Europe and South America. During the last two decades, even with the overall decrease, there has been an increase in proximal gastric cancers (those in the upper part of the stomach), which generally have a poorer prognosis than cancers in the body or outlet of the stomach. Stomach cancer has been associated with salted or smoked meat and fish, nitrates in the drinking water, smoking cigarettes and diets low in animal protein and fat. In addition, there is an increased risk of gastric cancer for those who have undergone partial removal of the stomach (subtotal gastrectomy) for ulcer disease and for those who have pernicious anemia.

Patients may present with a variety of symptoms, including weight loss, fatigue, loss of appetite and epigastric discomfort, at which time, a barium study or flexible upper endoscopy (with biopsy) is generally performed. For the small proportion with localized disease (less than 10%), curative surgery is the treatment of choice, but there is considerable debate as to the benefits of total versus subtotal gastrectomy and the degree of lymph node dissection (lymphadenectomy) required. Post-gastrectomy symptoms can include difficulty swallowing, bloating, diarrhea, flushing after eating and weight loss. Those who have only part of the stomach removed experience fewer of these symptoms and thus report having a better quality of life than patients who undergo a total resection. Chemotherapy (5-fluorouracil plus cisplatin) has become the standard treatment for advanced gastric cancer. Palliative surgery is considered when patients

suffer from pain, hemorrhage, perforation or obstruction, but is associated with a high level of post-operative morbidity.

Colorectal cancer (ICD-9 153 and 154)

In 2002, an estimated 17,600 new cases (9,500 men and 8,100 women) were diagnosed in Canada making colorectal cancer (CRC) the third most common cancer for each gender. In that year, there were an estimated 6,600 colorectal cancer deaths, with a ratio of deaths to new cases of 37% (fairly good prognosis).

Environmental factors, and especially dietary intake, may cause or promote colorectal cancer, which usually occurs in men and women over 40 years of age. Diets high in calories, cholesterol and fat and low in fibre appear to place individuals at higher risk of developing this disease. High alcohol consumption and certain occupational exposures can also increase the risk, in addition to inherited syndromes.

Many patients with CRC exhibit no symptoms, which highlights the importance of early detection programs and screening. Cases detected through screening are more likely to be treated at an earlier stage, with greater likelihood of cure. Approximately one-third of cases are diagnosed at each of three stages: localized stage, with regional nodal involvement or with distant metastatic disease. The liver is frequently the site of colorectal cancer metastasis. Symptomatic colon cancer presents with intermittent abdominal pain, nausea or vomiting, whereas symptomatic rectal cancer is more likely to present with rectal bleeding. Generally, rectal cancer, which represents almost one-third of all CRC cases, has a worse prognosis than colon cancer.

Surgery is the major treatment for those diagnosed with non-metastatic colon cancer. Lymph node dissection assists staging and can be therapeutic. Sphincter-sparing surgery for patients with early rectal cancer should always be considered before radical resection. The treatment objective for patients with locally advanced rectal cancer is to resect (remove) the tumour completely while attempting to minimize functional impairment and morbidity, such as impotence, urologic dysfunction and the need for a permanent colostomy (the surgical creation of an opening between the colon and the surface of the abdominal wall). Whereas almost one-third of rectal cancer patients will require a permanent colostomy, most colon cancers can be treated without one. Physical symptoms exhibited prior to surgery, such as loss of appetite, rectal bleeding, urgency of bowel movement and psychological distress, diminish following treatment.

For rectal cancer, adjuvant radiation therapy and chemotherapy can reduce the risk of local recurrence, but have associated toxicities. Depth of bowel-wall invasion and nodal status are used as indicators of the risk of local failure. There is a synergistic effect between combined radiotherapy and chemotherapy (chemoirradiation) in the treatment of rectal cancer. The combination reduces the risk of local failure and distant extrapelvic recurrence.

Some colon cancer patients can benefit from adjuvant chemotherapy following surgical

resection. The standard therapy for advanced systemic colorectal cancer is combination chemotherapy (particularly 5-fluorouracil or 5-FU and folinic acid with or without another drug). Since the majority of patients who recur do so within two years of their initial treatment, routine follow-up, preferably with colonoscopy, is generally initiated.

Patients managed successfully by surgery may live normal lives. However, if a colostomy is necessary, patients may limit their social activities for fear of embarrassment. Sexual relations are frequently impaired. Metastatic colorectal cancer is commonly associated with weight loss, loss of appetite, pain and progressive loss of strength and general well-being.

Pancreatic cancer (ICD-9 157)

The pancreas is located behind the stomach and in front of the first and second lumbar vertebrae, in the upper abdomen. In 2002, an estimated 1,550 men and 1,700 women were diagnosed with pancreatic cancer in Canada. The median age at diagnosis was 70 years of age. The ratio of deaths to new cases for pancreatic cancer was 99%, making it the cancer with the poorest prognosis for survival. This is partially explained by the inability to diagnose this cancer until after it has become locally advanced (40% of cases involve invasion of the duodenum or peripancreatic soft tissue and regional lymph nodes) or has metastasized (40% of cases have visceral involvement, usually to the liver). Fewer than 20% of cases are confined to the pancreas at the time of diagnosis and are potential candidates for resection.

The risk of pancreatic cancer rises as the amount and duration of cigarette smoking increase. Diets high in fat or meat consumption and with low intakes of fruits and vegetables add to the risk of this type of cancer. In addition, increased incidence appears to be associated with chronic pancreatitis, diabetes mellitus and some occupations that involve long-term exposure to solvents and petroleum compounds. Data on the impact of coffee and alcohol consumption are inconclusive. Recently, obesity and physical inactivity have also been shown to be associated with pancreatic cancer.

Patients with pancreatic cancer generally present with obstructive jaundice and upper abdominal or back pain. Marked loss of appetite, glucose intolerance, weight loss and fatigue are also common symptoms. Since so few patients are surgical candidates, accurate preoperative assessment of resectability is critical. Surgery generally involves removal of the pancreas, duodenum, gallbladder and bile duct (pancreaticoduodenectomy). This is generally followed by gastrointestinal reconstruction, which can be associated with various complications, including delayed gastric emptying and wound infection. In addition, patients may experience post-operative weight loss, thirst, frequent urination, fatigue and diabetes. Almost all patients experience pain, often described as gnawing, persistent, intense and devastating, during the course of their disease, to the point where some patients' will to live may be undermined. Patients with locally advanced and metastatic disease may benefit from chemotherapy, particularly from the drug gemcitabine.

Lung cancer (ICD-9 162)

In 2002, an estimated 12,000 men and 8,800 women were diagnosed with lung cancer in Canada, making this disease the second most common form of cancer for both genders. Almost 80% of all cases diagnosed were over 60 years of age. The estimated 18,400 deaths from lung cancer in 2002 (10,700 men and 7,700 women) represent almost 28 per cent of all cancer deaths in Canada, making this disease the leading cause of cancer death. The ratio of deaths to new cases for lung cancer was 88%, compared with 48% for all cancers, placing it in the "poor prognosis" category.

The predominant risk factor contributing to lung cancer is the number of cigarettes smoked and the duration of smoking. In addition, exposure to carcinogens such as asbestos, radon, passive smoke, hydrocarbons, chromium and nickel all appear to increase lung cancer risk. The choice of therapy for lung cancer is determined by the histological cell type—small cell or non-small cell—and the extent of disease at diagnosis. Non-small cell lung cancer accounts for over 80% of cases diagnosed. Almost two-thirds of all lung cancers are diagnosed at advanced stages, which limits therapeutic options.

Early stage non-small cell lung cancer is usually treated surgically, by lobectomy (removal of a lobe of the lung) or pneumonectomy (removal of the whole lung). Many of those diagnosed with locally advanced non-small cell lung cancer disease will receive radiotherapy in combination with chemotherapy. Patients diagnosed with metastatic disease are often dealing with high levels of comorbidity due to concomitant smoking-related illness and receive palliative chemotherapy and terminal care.

Small cell lung cancer cases are generally treated with chemotherapy and radiotherapy. Most with limited disease small cell lung cancer also receive prophylactic cranial irradiation, which is associated with a transient increase in fatigue, nausea and vomiting.

Lung cancer patients often present with a persistent cough, dyspnea (difficult or laboured breathing), decreased appetite and pain from pleural or chest wall involvement. Over 80% of those diagnosed with inoperable non-small cell lung cancer complain of fatigue, depressed mood and decreased energy. Reduced lung capacity as a result of surgery, radiation or underlying lung disease due to smoking often leads to reduced physical and role functioning.

Breast cancer (ICD-9 174)

Breast cancer is the most common malignancy affecting Canadian women (male breast cancer is uncommon and is not reviewed here). In 2002, an estimated 20,500 women were diagnosed with breast cancer and 5,400 died of the disease. The ratio of deaths to new cases was 26%, making this cancer among those with the best prognosis. Whereas incidence rates have leveled off since the early 1990s, mortality rates have been declining for over a decade.[2]

Risk factors that contribute to breast cancer are early age at menarche, nulliparity or late age at the time of first full-term pregnancy, late menopause, exposure to environmental toxins, genetic predisposition, and the use of

hormone replacement therapy. Evidence of the impact of diet and excessive use of alcohol are inconclusive.

In approximately 80% of cases, patients present with a palpable breast mass and have the diagnosis confirmed with a fine needle biopsy. Because of improved screening programs such as mammography, early stage breast cancer now represents almost 90% of all incident cases (small-to-medium-sized tumour, no or limited nodal involvement and no evidence of distant metastasis). Therapeutic options are dependent upon the stage of the disease at presentation, the age (almost 80% of cases occur in women aged 50 and older) and menopausal status of the patient, and the hormone receptor status of the tumour.

The majority of early stage breast cancers are treated surgically with breast-conserving surgery (excision of the primary tumour and adjacent breast tissue), followed by radiotherapy. Women diagnosed with loco-regional disease generally receive a modified radical mastectomy (excision of the breast with axillary node dissection) and many are now treated with pre-operative chemotherapy and post-operative radiotherapy. Standard therapies for metastatic breast cancer include hormonal therapy or chemotherapy.

Because breast cancer is among the more slow-growing tumours, life expectancy is often measured in years or decades, rather than in months. The quality of life of individuals with breast cancer is greatly influenced by the self-esteem issues experienced by the patient due to changed body image and altered sexual functioning. Following surgery, many women experience considerable arm morbidity due to arm swelling (lymphedema), as well as fear of cancer recurrence. Those undergoing chemotherapy and radiotherapy often exhibit chronic fatigue, nausea or pain, hot flashes and mood alterations, which interfere with well-being.

Prostate cancer (ICD-9 185)

Prostate cancer is the most frequent form of cancer diagnosed among Canadian men. In 2002, an estimated 18,200 cases were diagnosed, and 4,300 men died of the disease. Almost one-third of men over 50 years of age who die of other causes are found to have prostate cancer at autopsy. However, this type of cancer should not be considered a benign disease, since, if left untreated, it continues to progress slowly, but steadily.[3] Incidence increases more rapidly with age for prostate cancer than for any other cancer. Almost half of new cases and about 85% of deaths occur in men over 70 years of age.

The rise in the number of cases detected in the early 1990s can partially be explained by the increased use of screening techniques, such as the measurement of prostate-specific antigen (PSA) levels and transrectal ultrasonography (TRUS). Because tumour growth is promoted by androgens, men with high testosterone levels are at greater risk of developing prostate cancer. Diets with high monounsaturated fat intake, exposure to cadmium and genetic predisposition are also risk factors.

Because the prostate gland surrounds the urethra, patients with prostate cancer often have difficulty urinating, with symptoms such as hesitancy, incomplete bladder emptying or blood in the urine. They may also experience

pain or sudden impotence. The decision to manage early prostate cancer by treatment or by careful observation is controversial, since the two most common treatments for localized cancer, radical retropubic prostatectomy (removal of the prostate) or radiation therapy can result in urinary incontinence and/or erectile dysfunction.

Locally advanced prostate cancer is usually treated with external-beam radiation therapy and androgen ablation therapy (chemical castration). Treatments with curative intent are often unsuccessful, since many patients already have occult metastases.

When prostate cancer metastasizes, it spreads to lymph nodes and bone in over 80% of cases, which may require palliative radiation therapy for bone pain as well as androgen ablation therapy. Side effects include hot flashes, increased fatigue, loss of libido, impotence and weight gain.

Complications of long-term treatment are osteoporosis, depression and loss of muscle mass. Patients who have undergone prostatectomy may restrict social activities because of their concern over urinary incontinence. "Prostate cancer patients perceive pain, fatigue, impaired sexual life, urinary frequency and incontinence, and reduced professional life as having the greatest impact on the quality of their lives."[4] The emotional and cognitive burden of prostate cancer can affect self-esteem, self-image, masculinity and sexuality.

Bladder cancer (ICD-9 188)

In 2002, an estimated 5,000 new cases of bladder cancer were diagnosed (3,700 men and 1,300 women, most of whom were age 70 and over), making this the sixth most common cancer in Canada. It is considered a preventable disease since most cases result from exposure to environmental carcinogens. Both amount and duration of cigarette smoking have been shown to be correlated with bladder cancer incidence. There is also a high occupational risk for people exposed to aryl amines, such as those used in the paint, rubber and dye industries. The male to female ratio of bladder cancer is approximately three to one, but, in areas where cigarette smoking is common amongst women, this gap can narrow. Because the ratio of deaths to new cases for bladder cancer is 30%, compared with 48% for all cancers, this site is classified as one that has a very good prognosis. It should be noted that the ratio for women with bladder cancer is less favourable, at 36% (fairly good prognosis).

Hematuria (blood in the urine) and irritative symptoms such as urinary frequency are the most usual indicators. Cystoscopy and biopsy are the common methods of diagnosis. On presentation, almost 80% of all bladder cancers are considered to be superficial (limited to the mucous membrane lining, submucosa or connective tissue below). While low grade tumours rarely progress, bladder carcinomas are frequently multifocal (multiple areas of cancer) and can affect the entire urothelial tract. Higher grade muscle-invading tumours are much more likely to metastasize. Transurethral resection (TUR) can offer local control for most superficial bladder lesions, but cannot prevent recurrence.

While bladder preservation is always desirable, cystectomy (partial or complete removal of the bladder), high-dose local

irradiation, intravesical (within the bladder) immunotherapy and/or chemotherapy are often used to treat locally invasive, non-metastatic bladder cancer. For men, radical cystectomy involves not only removal of the bladder, but part of the urethra, the prostate and regional pelvic lymph nodes, which can lead to sexual dysfunction when nerve-sparing surgery is not performed. For women, radical cystectomy generally includes removal of the bladder, ovaries, uterus, entire urethra, lymph nodes and a segment of the vaginal wall. Following cystectomy, the patient must undergo the installation of a bladder substitute or urinary diversion, which may be associated with incontinence, impotence in men, and recurrent infection. For those with regionally invasive disease who are not considered good candidates for cystectomy, radiotherapy alone is a treatment option, but combined modality therapies can also be considered.

Patients with advanced cancer may experience hemorrhage, pelvic or flank pain, or rectal obstruction with constipation. Radiotherapy or chemotherapy can reduce symptoms and the administration of combination chemotherapy can extend survival for some patient populations.

Renal (kidney) cancer (ICD-9 189)

In 2002, an estimated 2,500 men and 1,500 women were diagnosed with renal cancer, the seventh most frequently diagnosed cancer in Canada. Renal cell cancer is the most common type of kidney cancer, representing approximately 85% of all cases. The ratio of deaths to new cases was 36% (fairly good prognosis), compared with the average of 48% for all cancers. Most cases are diagnosed between the ages of 50 and 70 years. Risk factors include living in an urban setting, cigarette smoking, analgesic abuse, obesity and exposure to environmental toxins (asbestos and cadmium).

Approximately 45% of patients present with localized disease, 25% have locally advanced cancer and 30% present with metastatic disease (generally in the lung, bone, or brain). In many cases, renal cancers are discovered incidentally during radiographic procedures such as ultrasound or computed tomography. Often, patients are asymptomatic until the disease has become more advanced, at which time, they may present with pain, hematuria (blood in the urine) and flank mass.

Either radical or partial nephrectomy (complete or partial removal of the kidney) is the standard treatment for localized renal cancer. Removal of the lymph nodes (regional lymphadenectomy) is generally performed at the same time. While lymph node dissection is useful for staging, there is ongoing debate as to whether it prolongs survival. Radical surgery includes removal of the kidney and surrounding tissues, including the adrenal gland. When both kidneys are involved, one is removed and a partial nephrectomy is performed on the remaining organ, if possible. Radical surgery and dialysis with possible later renal transplantation is a less favoured option.

While localized kidney cancer is often cured by surgery, treatment for metastatic disease is generally unsuccessful. Palliative surgery for metastatic renal cancer rarely cures the disease but may increase survival. Palliative radiotherapy may relieve pain, but renal cell carcinoma appears to be chemotherapy-

resistant and not responsive to hormonal therapy.

Many patients with renal carcinoma develop systemic symptoms: anemia due to loss of blood in the urine, fever, fatigue, malnutrition, wasting and weight loss.

Non-Hodgkin's lymphoma (ICD-9 200 and 202)

In 2002, an estimated 6,300 Canadians (3,400 men and 2,900 women) were diagnosed with non-Hodgkin's lymphoma (NHL), the fifth most frequently diagnosed cancer in Canada. The ratio of deaths to new cases was 45% (fairly good prognosis). The median age at diagnosis is 65 years, but incidence peaks in the 80 to 85 year age group.

NHLs are a diverse group of cancers originating in the lymphoid system, which includes the lymph nodes as well as extranodal sites such as the stomach, small intestine, skin and brain. Lymphocytes are produced by the lymph nodes to provide immunity against infection: B cell lymphocytes produce antibodies and T cell lymphocytes provide cell-based immunity. Exposure to environmental toxins, viruses and congenital or acquired immunosuppression can cause lymphocytes to develop into malignant lymphomas, with B cell lymphomas being more common than T cell. NHLs develop in up to 30% of those infected with human immunodeficiency virus (HIV) and almost half are associated with the Epstein-Barr virus infection. Patients undergoing organ transplantation and receiving immunosuppressive drugs are very likely to develop NHL.

NHLs are somewhat paradoxically divided into "indolent" (incurable) and "aggressive" (potentially curable) lymphomas. Indolent lymphomas usually present with widespread involvement of the lymph nodes, spleen, liver or bone marrow and are considered incurable. However, they tend to grow slowly and as many as half of those diagnosed may have their initial therapy deferred for several years ("watch and wait"). For some patients, this lack of treatment may create stress and anxiety. For most patients with indolent NHL, the primary goal of therapy is to achieve lengthy survival with a good quality of life. When typical lymphoma symptoms such as weight loss, fever and sweating appear, treatment becomes necessary. Weakness, malaise, poor appetite, decreased stamina, in addition to uncomfortable lymphadenopathy (swelling of the lymph nodes) are commonly present.

Early stage indolent NHLs are treated with either chemotherapy or localized radiation therapy. Those with advanced stage symptomatic disease are often treated with either a single chemotherapy agent or a combination of drugs, with almost three-quarters achieving a complete remission. However, the vast majority will become resistant to treatment and will eventually relapse. Approximately 40% of indolent cases will convert to diffuse aggressive lymphoma.

Approximately three-quarters of patients with "aggressive" NHL present with advanced stage disease, which can progress rapidly. However, if a patient achieves a complete response, cure can still be achieved. The treatment standard is single agent chemotherapy, with or without involved field

radiation for early stage cancer, and combination chemotherapy alone for advanced stage. Combination chemotherapy is known to produce many toxicities, including hair loss, nausea, fatigue, constipation and bone marrow suppression. For patients who relapse after achieving a remission, salvage chemotherapy followed by autologous bone marrow transplantation is the only treatment that can produce long-term remission.

Leukemia (ICD-9 204)

Leukemia is a cancer of the body's blood-forming tissues, including the bone marrow and lymphatic system. The word means "white blood" in Greek, since the blood takes on a whitish tone as abnormal white blood cells (lymphocytes) accumulate and block the production of normal blood cells in the bone marrow. Leukemia is categorized according to the type of white blood cell that is involved (lymphoid or myeloid) and how rapidly it develops (acute or chronic). In this disease, the production of red blood cells and platelets is also affected, which can lead to fatigue from anemia or bleeding or easy bruising due to impaired ability to form blood clots.

In 2002, an estimated 3,650 new cases of leukemia (2,100 men and 1,550 women) were diagnosed in Canada. In adults, there are four major types of leukemia: acute lymphocytic (ALL), acute myeloid (AML), chronic lymphocytic (CLL) and chronic myeloid (CML). Although there is a perception that leukemia is a disease of children, adults are ten times more likely to develop it. In 2002, it was estimated that fewer than 350 children were diagnosed with leukemia in Canada.

Little is known about the causes of leukemia, although post-natal exposure to radiation (therapeutic doses for medical conditions or military radiation exposure) has been suggested as a risk factor for acute leukemias. Leukemia develops more frequently in men, Caucasians and those in higher socio-economic groups and has been linked to exposure to benzene and other toxins, radon, cigarette smoke and certain viruses. Those born with Down's syndrome have a twenty-fold risk of developing leukemia. Chromosome damage due to the administration of chemotherapeutic agents has been linked to the development of secondary leukemias.

While leukemia can present in a variety of ways, anemia, thrombocytopenia (low blood platelets) and severe and persistent fatigue are common presenting signs and symptoms. An enlarged liver and spleen and swollen lymph nodes may also be present. A bone marrow aspiration and biopsy are required to establish a definitive diagnosis of leukemia. As the name implies, acute leukemias tend to have a more sudden onset of symptoms, whereas chronic leukemias are more gradual in their onset and run a more indolent course. This chapter includes two types of leukemia: chronic lymphocytic leukemia (CLL), the most common leukemia among adults, and acute lymphoblastic leukemia (ALL), the most common leukemia among children.

Chronic lymphocytic leukemia (CLL)

Chronic lymphocytic leukemia (CLL) is the most common adult leukemia in the western world. CLL is considered a disease of the elderly; it is rarely diagnosed before the age

of forty (90% of cases of all chronic leukemias are over fifty). The low incidence of CLL in Asian countries is thought to be due to genetic differences, rather than environmental factors.

CLL is always suspected when there is an excess of lymphocytes in the blood, as well as the bone marrow. Many cases of CLL are diagnosed during a routine blood test. Because patients with early stage CLL are often asymptomatic, and can live for long periods without requiring therapy, it is often difficult to determine when to initiate treatment. As an example, early stage indolent or "smoldering" CLL has a survival equivalent to an age-and sex-matched healthy population. However, the natural history of CLL can be extremely variable.

Chronic leukemia cells are often slow to multiply and are therefore less sensitive to chemotherapy. However, it is generally believed that symptomatic CLL (fever, unintended weight loss, profuse night sweats and enlarged lymph nodes) should be treated with systemic therapy usually consisting of alkylating agents, sometimes combined with purine analogues or monoclonal antibodies. Those diagnosed with more aggressive, advanced disease (approximately 25% of CLL cases) are at high risk for rapid progression and lower survival.

There is no evidence that long term systemic therapy is beneficial. Because of the advanced age of most CLL patients, only about 10% of them qualify for bone marrow transplantation. It is generally offered to those who are less than fifty-five years of age. Patients with CLL are thought to be at higher risk of developing second malignancies, such as lung cancer or cancer in the gastrointestinal tract. The most frequent cause of death for CLL patients is severe systemic infections, such as pneumonia or septicemia.

Childhood acute lymphoblastic leukemia (ALL)

Leukemia is the most common form of childhood malignancy, accounting for 30% of all childhood cancer. The incidence of leukemia is increased in children with certain chromosomal abnormalities. Over three-quarters of the cases of childhood leukemia are acute lymphoblastic leukemia (ALL). The peak incidence of ALL is between three and six years of age and the disease is more common in boys. Twenty per cent of cases are acute myeloid leukemia and less than 5% are chronic myeloid leukemia (CLL is rarely diagnosed in children).

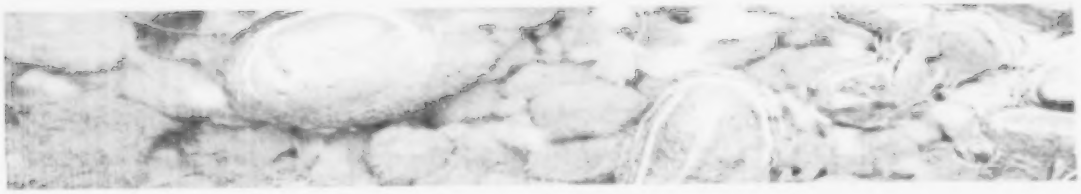
Children with leukemia are generally symptomatic one to six weeks prior to diagnosis. The symptoms reflect the degree to which the bone marrow has been infiltrated with leukemic white cells. Anemia and thrombocytopenia (reduced platelet count) are present in more than two-thirds of patients; these lead to easy fatigability, headache and malaise, as well as bruising and bleeding from the gums and nose. Skin pallor, fever, bone tenderness and enlarged lymph nodes are common.

In the 1950s, when children were diagnosed with leukemia, there were few treatment options and those therapies available were intended to palliate the symptoms, not cure the disease. Today, as a result of extensive basic and clinical research, therapy commonly achieves a complete remission, which implies a return to normal in the blood

counts and bone marrow. "Remission induction therapy" generally includes several chemotherapy drugs, which can induce complete remission within four weeks of initiation of therapy. More than ninety per cent of children with ALL achieve complete remission after three to four weeks of induction therapy, compared with 60% to 80% of adults. With timely, adequate and intensive treatment, over 70% of children with ALL are now cured. Infections, organ dysfunction and hair loss are common adverse events during remission induction therapy.

A complete remission is followed by high doses of postinduction chemotherapy, which is designed to kill any remaining leukemia cells in the bone marrow, lymphatic system or blood stream. Prophylactic chemotherapy and/or radiotherapy is routinely directed to the central nervous system; otherwise, this would be a common site of spread. After complete remission is achieved, a period of "maintenance therapy" is begun to eliminate all residual leukemia cells and prevent relapse. Maintenance therapy consists of a variety of chemotherapeutic regimens, and can last from two to four years.

During induction chemotherapy, severely low blood cell counts result in most patients experiencing fever, thus requiring broad spectrum antibiotic treatments and red blood cell and platelet transfusions. Despite prophylactic antibiotics and platelet transfusions, induction chemotherapy can still result in death from infection and hemorrhage. The prognosis of those who fail to achieve remission, or relapse after achieving remission, is poor. Approximately one-third of patients who relapse will achieve a second remission, which is generally of shorter duration than the first. While controversial, bone marrow transplantation is often attempted for selected patients in first remission.



At diagnosis

This section presents the context and descriptions for 21 health states that cover the course and treatment of cancer. These health states were developed based on the cancers presented in the previous section.

For the purposes of this document, most cancers were classified according to their likely prognosis, as well as therapeutic intent. These prognostic groups are from *Canadian Cancer Statistics*.[2] This classification was used on the assumption that cancers with similar prognoses would have similar effects on individuals, in terms of limitations to their functional capacities. (Descriptions for two types of leukemia are provided separately.)

The prognostic category "very good" (ratio of deaths to new cases [d/c] of 30% or less) includes the following cancers: breast, prostate, bladder, testicular, uterine, thyroid, cervical, melanoma* and Hodgkin's disease. These cancers would generally be diagnosed at an early stage (almost 90% of breast cancer patients are diagnosed at an early stage) and would be treated with curative intent.

Cancers with a "fairly good" prognosis (d/c of greater than 30% but less than 50%) include colorectal, renal, oral and laryngeal, non-Hodgkin's lymphoma, and bone and connective tissue.** These are often diagnosed at a later stage, or behave in an aggressive fashion, which implies less chance for cure.

Finally, cancers classified as having a "poor prognosis" (d/c 50% or greater) include lung, pancreatic, stomach, ovarian, brain, liver,** gall bladder,** esophageal and multiple myeloma. These are usually not diagnosed until the disease has progressed (approximately 70% of lung cancers are diagnosed at an advanced stage), and are treated with palliative intent.

This classification approach applies to most, but not all, the cancers listed above. Under certain circumstances, cancers which are considered "curable" are diagnosed at an advanced stage, but highly effective therapy is available. On the other hand, "poor prognosis" cancers are sometimes diagnosed early enough to be treated with curative intent.

This section provides generic descriptions based on a literature review of the three most common cancers in each prognostic group. The patients' physical and emotional states at the time of diagnosis of local or regional disease are expected to apply to any of the cancers in the category (as indicated in the descriptions). One health state at the time of diagnosis of metastatic disease is also described.

* Non-melanoma skin cancers are excluded from this classification and from *Canadian Cancer Statistics* because they are usually successfully treated without requiring hospitalization and because reporting procedures vary across the country, making consistent registration of these cancers difficult.

** These cancers were omitted from *Canadian Cancer Statistics* and have been classified based on case fatality data from the Surveillance, Epidemiology, and End Results (SEER) Program.[3]

Cancers with a very good prognosis

Description

This description applies to the health state at diagnosis of local or regional disease, prior to the commencement of treatment. It describes patients diagnosed with breast, prostate and bladder cancer, but also applies to cancer of the uterus, thyroid, cervix and testis, melanoma and Hodgkin's disease. Patients report depression, impotence, urinary difficulties (for bladder and prostate cancers) and impaired sexual functioning as well as decreases in self esteem and self-image. Duration of this phase is estimated to be 37 days.[6]

Classification	Core	Supplementary
	1 1 3 1 1 2	3 1 1 1 1

Cancers with a fairly good prognosis

Description

This description applies to the health state at diagnosis of local or regional disease, prior to the commencement of treatment. It describes patients diagnosed with colorectal cancer, non-Hodgkin's lymphoma and renal (kidney) cancer, but also applies to oral and laryngeal cancer and cancer of the bone and connective tissue. Many patients with these cancers experience general malaise, fever, fatigue, loss of appetite, decreased stamina, psychological distress (including stress and anxiety) and impaired social and sexual relations. Duration of this phase is estimated to be 37 days.[6]

Classification	Core	Supplementary
	2 2 3 2 1 2	3 1 1 1 1

Cancers with a poor prognosis

Description

This description applies to the health state at diagnosis of local or regional disease, prior to the commencement of treatment. It describes patients diagnosed with lung, pancreatic and stomach cancer but also applies to cancer of the ovary, brain, esophagus, gall bladder, liver and multiple myeloma. Marked loss of appetite, weight loss, chest, abdominal or back pain, fatigue, depressed mood and decreased physical functioning are common symptoms. In addition, lung cancer patients often present with a persistent cough and dyspnea. Duration of this phase is estimated to be 37 days.[6]

Classification	Core	Supplementary
	2 2 3 2 1 3	3 1 1 1 1

Metastatic disease

Description

This description applies to any cancer that is diagnosed after it has metastasized (spread to other parts of the body), generally referred to as Stage IV disease. It also applies to any cancer that is initially diagnosed at an earlier stage, but has metastasized at the time of recurrence.

While radiotherapy and chemotherapy are viable therapeutic options for treating metastatic disease, the treatment objective is palliative, rather than curative. Surgical interventions may be necessary to manage tumour-induced obstruction of the esophagus, bowel, bladder or other structures, or to repair bones weakened by cancer that have fractured. The functional limitations of patients living with metastatic disease will be dependent on the site of metastasis.

Patients complain of pain severe enough to compromise daily functioning, as well as progressive loss of strength and weight loss. Sadness, grief and depression are also common in life-threatening illness. Fatigue is a serious and disabling side effect of metastatic disease. Many patients experience confusion and have difficulty concentrating. In addition, social impairment, marital and relationship stress and direct interference with sexual functioning can lead to high levels of anxiety and feelings of helplessness and hopelessness. Duration of this phase is estimated to be 37 days.

Classification	Core	Supplementary
	3 2 4 3 2 3	4 1 1 1 1

Chronic lymphocytic leukemia (CLL)

Description

This description applies to chronic lymphocytic leukemia at diagnosis and before treatment. Many individuals with early stage CLL are asymptomatic, but may be identified during a routine blood test when they present with infections, fatigue, or lymphadenopathy. Individuals may live in this health state for long periods without requiring therapy.

Patients with CLL suffer from the discomfort of enlarged lymph nodes and/or, liver and spleen, recurring infections, persistent fatigue and night sweats. In addition, they may experience more frequent hospitalizations, uncomfortable medical procedures, decreased social interaction, stress over their chronic illness and fear of death.

Classification	Core	Supplementary
	2 2 2 2 1 2	3 1 1 1 1

Cancers with a very good prognosis

Description

This description applies to the health state at diagnosis of local or regional disease, prior to the commencement of treatment. It describes patients diagnosed with breast, prostate and bladder cancer, but also applies to cancer of the uterus, thyroid, cervix and testis, melanoma and Hodgkin's disease. Patients report depression, impotence, urinary difficulties (for bladder and prostate cancers) and impaired sexual functioning as well as decreases in self esteem and self-image. Duration of this phase is estimated to be 37 days.*

Classification	Core	Supplementary
	1 1 3 1 1 2	3 1 1 1 1

Cancers with a fairly good prognosis

Description

This description applies to the health state at diagnosis of local or regional disease, prior to the commencement of treatment. It describes patients diagnosed with colorectal cancer, non-Hodgkin's lymphoma and renal (kidney) cancer, but also applies to oral and laryngeal cancer and cancer of the bone and connective tissue. Many patients with these cancers experience general malaise, fever, fatigue, loss of appetite, decreased stamina, psychological distress (including stress and anxiety) and impaired social and sexual relations. Duration of this phase is estimated to be 37 days.*

Classification	Core	Supplementary
	2 2 3 2 1 2	3 1 1 1 1

Cancers with a poor prognosis

Description

This description applies to the health state at diagnosis of local or regional disease, prior to the commencement of treatment. It describes patients diagnosed with lung, pancreatic and stomach cancer but also applies to cancer of the ovary, brain, esophagus, gall bladder, liver and multiple myeloma. Marked loss of appetite, weight loss, chest, abdominal or back pain, fatigue, depressed mood and decreased physical functioning are common symptoms. In addition, lung cancer patients often present with a persistent cough and dyspnea. Duration of this phase is estimated to be 37 days.*

Classification	Core	Supplementary
	2 2 3 2 1 3	3 1 1 1 1

Metastatic disease

Description

This description applies to any cancer that is diagnosed after it has metastasized (spread to other parts of the body), generally referred to as Stage IV disease. It also applies to any cancer that is initially diagnosed at an earlier stage, but has metastasized at the time of recurrence.

While radiotherapy and chemotherapy are viable therapeutic options for treating metastatic disease, the treatment objective is palliative, rather than curative. Surgical interventions may be necessary to manage tumour-induced obstruction of the esophagus, bowel, bladder or other structures, or to repair bones weakened by cancer that have fractured. The functional limitations of patients living with metastatic disease will be dependent on the site of metastasis.

Patients complain of pain severe enough to compromise daily functioning, as well as progressive loss of strength and weight loss. Sadness, grief and depression are also common in life-threatening illness. Fatigue is a serious and disabling side effect of metastatic disease. Many patients experience confusion and have difficulty concentrating. In addition, social impairment, marital and relationship stress and direct interference with sexual functioning can lead to high levels of anxiety and feelings of helplessness and hopelessness. Duration of this phase is estimated to be 37 days.

Classification	Core	Supplementary
	3 2 4 3 2 3	4 1 1 1 1

Chronic lymphocytic leukemia (CLL)

Description

This description applies to chronic lymphocytic leukemia at diagnosis and before treatment. Many individuals with early stage CLL are asymptomatic, but may be identified during a routine blood test when they present with infections, fatigue, or lymphadenopathy. Individuals may live in this health state for long periods without requiring therapy.

Patients with CLL suffer from the discomfort of enlarged lymph nodes and/or, liver and spleen, recurring infections, persistent fatigue and night sweats. In addition, they may experience more frequent hospitalizations, uncomfortable medical procedures, decreased social interaction, stress over their chronic illness and fear of death.

Classification	Core	Supplementary
	2 2 2 2 1 2	3 1 1 1 1

Childhood acute lymphoblastic leukemia (ALL)

Description

This description applies to childhood acute lymphoblastic leukemia at diagnosis and before treatment. Children with ALL may experience swollen lymph nodes, easy bruising, nosebleeds, frequent infections and fever, and excessive sweating. In addition, they frequently suffer from persistent fatigue due to anemia, emotional strain, and anxiety; they experience separation from their family when hospitalized, disrupted schooling and limitations to their social lives. Children with leukemia are generally symptomatic one to six weeks prior to diagnosis.

Classification	Core	Supplementary
	2 3 3 3 1 3	**3 1 1 1 1**

Therapeutic options

When cancer occurs, the common therapeutic options are surgery, radiotherapy, and chemotherapy. These may be administered alone or in various combinations. Hormonal therapy is commonly used as a first line therapy for prostate cancer. The choice of treatment depends on the size and location of the tumour, the extent of tumour spread, the patient's age and general health. Each therapeutic option can have an impact on any or all of the functional abilities of the individual. The level of dysfunction that patients experience will depend on the type of therapy they undergo and their own coping skills.

These descriptions apply to the health state experienced during cancer therapy (or following therapy in the case of surgery) and the following considerations should be noted:

- only the short-term impact of the therapy is included, for example, the description for "after surgery" includes only the three to five weeks following the surgical procedure; the descriptions for radiotherapy and chemotherapy apply to the time during which the therapy is being administered;

- many cancer patients receive more than one therapeutic modality. To understand their true emotional and physical state, the cumulative effects of the diagnosis of cancer, as well as administration of the various therapies, would have to be considered.

Surgery

Surgery is the most frequently used cancer therapy and cures more patients than any other single treatment modality. Surgery is necessary to determine whether a growth is benign or malignant and to obtain tissue that can determine the type of cancer and extent of spread at the time of diagnosis. For small, localized, easily accessible tumours, a complete resection (removal) of the tumour and surrounding margins (tissue around the tumour and perhaps nearby lymph nodes) can be performed with curative intent. For more advanced disease, total removal of the cancerous organ might be necessary.

Following in-patient surgery

Description

The majority of surgical procedures for cancer are performed in-hospital. For the nine cancers studied (other than leukemia), the common procedures performed are complete or partial resection of the organ (resection is indicated by the suffix "ectomy"). They are mastectomy or lumpectomy for breast cancer, prostatectomy for prostate cancer, cystectomy for bladder cancer, colostomy or resection of rectum for colorectal cancer, nephrectomy for kidney cancer, gastrectomy for stomach cancer, lobectomy or pneumonectomy for lung cancer, and pancreaticoduodenectomy for pancreatic cancer.

This description includes the post-operative effects of any surgery that requires an overnight stay in hospital, even if just for one night and typically lasts between 3-5 weeks. For many patients, the surgical procedure confirms the diagnosis of cancer, resulting in uncertainty and fear about the future, not only in terms of survival, but also about additional therapies that might have to be undergone. Side effects following surgery can range from mild to severe. Some patients experience minor discomfort for a few days, whereas those treated with more radical procedures may endure long-term discomfort and dysfunctionality. Common experiences are arm morbidity following mastectomy for breast cancer; incontinence and/or impotence after prostate cancer surgery; difficulty breathing after removal of a lung; or the psychological impact of a colostomy after colorectal cancer. In addition, many breast, prostate, bladder and colorectal cancer patients experience problems with sexuality and self-esteem following surgical treatment. Post-operative fatigue is generally quite significant and of long duration.

Classification	Core	Supplementary
	2 3 3 3 1 3	**3 1 1 1 1**

Following out-patient surgery

Description

The only surgery consistently performed on an out-patient (ambulatory) basis is lumpectomy or breast conserving surgery for early stage breast cancer. Patients may experience pain and discomfort (due to the insertion of drains) and some arm morbidity following the surgery. They may also be quite anxious and uncertain about future recurrences and potential adjuvant therapies.

Classification	Core	Supplementary
	2 2 3 2 1 2	**3 1 1 1 1**

Radiotherapy (radiation therapy)

Radiotherapy uses high-energy radiation from a linear accelerator or other radiotherapy machine to damage or kill cancer cells. The treatment objective is to target a specific cancerous area, while minimizing damage to surrounding healthy tissue. Radiotherapy may be administered pre-operatively to shrink the tumour to facilitate surgery (e.g., for rectal cancer), or may be given as adjuvant therapy post-operatively to reduce the probability of local recurrence (e.g., of breast cancer, following breast conserving surgery). It is sometimes combined with chemotherapy (chemoirradiation) (e.g., for locally advanced lung cancer).

Radiotherapy may be used to "cure" some cancers (radical radiotherapy), but it can also effectively palliate symptoms and improve quality of life when "cure" is not possible. While radiotherapy is most often administered on an out-patient basis, hospitalization may be required if the patient has co-morbid conditions, or if radioactive sources are being implanted directly into the area of the tumour.

While receiving curative radiotherapy

Description

Local radical or curative radiotherapy may be used as the sole therapeutic agent for a number of potentially curable cancers. It is generally provided at a hospital or clinic five days a week for five or more weeks. Side effects of radiotherapy depend on the treatment dose and the part of the body being treated. Patients experience mild discomfort and moderate levels of anxiety while undergoing radiotherapy. Fatigue appears to be the most common side effect and one which has the most profound impact on quality of life. Local skin changes (itching, tenderness, swelling or soreness), nausea and vomiting, diarrhea and ulceration of the radiated area may also occur.

Classification	Core	Supplementary
	3 2 3 3 1 2	**3 1 1 1 1**

While receiving palliative radiotherapy

Description	Palliative radiotherapy is used to provide pain relief and improve quality of life when curative therapy has failed or is not an option. It is usually administered in low doses and with a short duration (less than four weeks) and is sometimes given only once. Patients may experience mild discomfort while undergoing palliative radiotherapy and most experience fatigue. As patients recognize that the treatment is non curative, they are often very anxious and uncertain about their future and may withdraw from social relationships at this time.
Classification	Core: **2 3 4 4 2 4** Supplementary: **3 1 1 1 1**

Chemotherapy

Chemotherapy is the term used to describe a variety of drugs that kill or inhibit the growth of cancerous cells. Unlike surgery or radiotherapy, chemotherapy is systemic, meaning that the drugs are usually injected into a vein and flow through the bloodstream to almost every part of the body. The drugs damage newly forming cells. Patients usually receive their treatments at intervals of every three to four weeks in an out-patient environment, such as a clinic or at home, often over a period of six months. However, because of the toxicity associated with some chemotherapy combinations, a short hospital stay may be necessary.

Chemotherapy may be used to cure, control or palliate cancer. Pre-operative or neoadjuvant chemotherapy may be used to reduce the size and extent of the primary tumour, to facilitate complete surgical excision. Chemotherapy is commonly used as adjuvant therapy after local treatment with surgery or radiotherapy to eradicate or suppress minimal residual disease, decrease the rate of relapse or improve survival. In cases where a cure is not possible, chemotherapy is often administered to relieve symptoms, prolong life and enhance quality of life.

Depending on the specific drugs used, chemotherapy can produce mild, moderate or severe side effects. The most common reactions, nausea and vomiting, are now being treated more successfully with anti-emetics (stemetil, ondansetron or related medications), which can prevent or relieve these symptoms. The type of cancer and stage at diagnosis will determine which health state applies during chemotherapy.

While receiving chemotherapy (mild toxicity)

Description

This description is based on the regimens of chemotherapeutic agents used to treat loco-regional colon cancer (5-fluorouracil [5FU] with folinic acid) and metastatic pancreatic cancer (gemcitabine [Gemzar]).

When individuals receive chemotherapeutic agents that have mildly toxic side effects, they generally experience mild nausea (anti-emetics are usually administered), some diarrhea and a relatively low risk of hospitalization for fever or dehydration. Fatigue is a commonly reported side effect.

Duration of treatment is estimated to be six months.

Classification	Core	Supplementary
	2 2 3 3 2 3	**3 1 1 1 1**

While receiving chemotherapy (moderate toxicity)

Description

This description is based on the regimens of chemotherapeutic agents used to treat loco-regional and metastatic breast cancer (anthracycline based regimens), lung cancer (cisplatin with other agents), metastatic bladder cancer (gemcitabine with cisplatin), loco-regional non-Hodgkin's lymphoma (CHOP—cyclophosphamide, doxorubicin [Adriamycin], vincristine [Oncovin] and prednisone, with or without rituximab [Rituxan]), and metastatic stomach cancer (doxorubicin [Adriamycin] plus cisplatin).

Individuals receiving chemotherapeutic agents that have moderately toxic side effects generally experience moderate to severe nausea and vomiting (the effects of which are lessened with anti-emetics), weakness, hair loss, neuropathy (nerve damage), risk of infection and a moderate risk of being hospitalized for fever or neuropathy. Patients describe their side effects as including discomfort, fatigue and anxiety. Social relationships can be disrupted due to decreased sexual desire and mood swings and some patients experience parasthesia (an abnormal touch sensation, such as burning or prickling in their fingers or toes) which can create difficulty buttoning clothes or tying shoes.

Duration of treatment is estimated to be six months.

Classification	Core	Supplementary
	2 2 3 3 2 3	**3 1 1 1 2**

While receiving chemotherapy (severe toxicity)

Description

This description is based on the regimen of chemotherapeutic agents used to treat metastatic colon cancer (irinotecan with 5-fluorouracil and folinic acid), which may require the administration of anti-emetics, as well as anti-diarrheal medicines.

Patients generally experience severe nausea and vomiting (the effects of which are lessened with anti-emetics) and very severe diarrhea, with a high risk of hospitalization for neutropenic fever and dehydration. They may also complain of sensitive skin, cough, sore muscles, severe mouth sores, moderate epigastric distress, shortness of breath (dyspnea), weakness and dizziness. Some patients experience paresthesia in their hands and feet. Patients' capacities to sustain social relationships can be compromised during the administration of chemotherapeutic agents which have severely toxic side effects, due to fatigue, anxiety, depression and irritability.

Duration of treatment is estimated to be six months.

Classification	Core	Supplementary
	2 2 3 3 2 4	**3 1 1 1 2**

Hormonal therapy

Some types of cancer, including most breast and prostate cancers, depend on hormones to grow. Hormonal levels can be reduced by surgically removing the organs that produce them (testes or ovaries) or by administering drugs that stop hormone production or block their effects. This health state is based on hormonal therapy, which is routinely used as a first-line therapy for prostate cancer.

While receiving hormonal therapy

Description

Generally, hormonal ablation therapy (chemical castration) is used as the standard treatment for the management of symptomatic metastatic prostate cancer, which usually presents with bone pain. While the pain decreases in the majority of cases, important side effects are impotence or loss of sexual desire, which can be temporary, long lasting or permanent. Many men also experience hot flashes, breast tenderness, loss of muscle mass, increased fatigue and weight gain, which compromises their self-esteem and masculinity.

While the duration of treatment depends on the stage of disease at diagnosis, the average duration of hormonal therapy is three months for local or regional diagnosis and eighteen months for metastatic disease.

Classification	Core	Supplementary
	1 2 2 3 2 2	2 1 1 1 1

Bone marrow transplantation

Bone marrow transplantation is a treatment for leukemia during which malignant cells are eliminated through the use of high-dose chemotherapy and/or radiation. This is followed by bone marrow or peripheral blood stem cell rescue in order to restore hematological and immunological function. The objective of bone marrow transplantation is to provide a healthy stem cell population that will differentiate into blood cells to replace deficient or pathologic cells of the host. Autologous bone marrow transplantation involves using an individual's own bone marrow which has been purged of cancer through chemotherapy and/or radiotherapy. In allogeneic bone marrow transplantation, healthy bone marrow from a compatible donor is used.

Following bone marrow transplantation

Description

This description is for the immediate post-surgery recovery period, which lasts four to six weeks. The first two to three weeks after bone marrow transplantation has been performed are critical, as the establishment of the new graft takes 10 days to three weeks. During this time, patients are without marrow function, making them susceptible to infection and vulnerable to bleeding. In addition, they may experience shortness of breath, wheezing, flank or back pain, fever, mouth ulcers and diarrhea. Patients must undergo long periods of hospitalization, isolation from friends and family and high levels of stress.

Classification	Core	Supplementary
	3 2 2 2 1 3	3 1 1 1 1

Subsequent health states

Remission

Patients are considered in remission after treatment when there is no clinical evidence of cancer; more generally, remission refers to the period following treatment. Patients may remain in this state until they die from some other cause or they may have a recurrence of their cancer. While in remission, patients do not exhibit any signs of cancer, but might experience residual physical or psychological effects, most commonly from the treatments received. In addition, many cancer patients "in remission" live with the concern and fear that their cancer may recur. These definitions were developed from literature and are based on three of the most common cancers in each prognostic group. Individuals often undergo two or more types of treatments and may experience the combined long-term effects of multiple treatments.

Remission after surgery

Description	This description includes the long-term effects of having had surgery only, not in combination with any other therapy. Fatigue, insufficient sleep and insomnia are reported following surgery. Patients requiring radical surgery frequently report severely restricted social and sexual activities. Breast cancer patients experience numbness, pain and swelling in the affected arm; lung cancer patients complain of dyspnea; those having surgery for colorectal or prostate cancer can experience persistent bowel and/or bladder problems. Anxiety and psychological distress can result from follow-up visits.	
Classification	Core	Supplementary
	2 2 2 2 1 3	2 1 1 1 1

Remission after radiotherapy

Description

This description includes the long-term effects of having had radiotherapy alone, not in combination with any other therapy. Chronic fatigue and distress are frequently reported following radiotherapy. While most side effects are temporary, there are some long-term chronic reactions to radiotherapy that are permanent, such as radiation-induced scarring of the tissues (e.g., lung fibrosis) or within the abdomen, leading to bowel obstruction. Bladder and bowel cancer patients report irritative bladder or bowel symptoms and rectal cancer patients may experience inflammation of the rectum. Rarely, radiotherapy can lead to the late induction of second malignancies.

Classification	Core	Supplementary
	2 2 2 3 1 2	2 1 1 1 1

Remission after chemotherapy

Description

This description includes the long-term effects of having had chemotherapy alone (at any level of toxicity), not in combination with any other therapy. Many patients exhibit chronic fatigue (referred to as off-treatment fatigue), energy loss, sleep dysfunction, problems with memory and attention. Some women experience hot flashes and mood alterations as well as sexual dysfunction (due to menopausal symptoms, painful intercourse, poor body image or low libido) following chemotherapy. Other side effects reported are employment and marital problems, familial disruptions and anxiety. Damage to the reproductive system can result in short- or long-term infertility and sexual problems for both men and women. Second malignancies may occur years later as a result of the chemotherapy administration.

Classification	Core	Supplementary
	2 2 2 2 2 2	2 1 1 1 1

Remission after hormonal therapy

Description

This description includes the long-term effects of having had only hormonal therapy for prostate cancer, not in combination with any other therapy. Patients may experience hot flashes and breast tenderness, fatigue, lethargy, loss of libido and sexual impotence, which can be temporary, long lasting or permanent.

Classification	Core	Supplementary
	1 2 2 3 1 2	2 1 1 1 1

Recurrence

Cancer may recur after the initial treatment. A specific health state for recurrence is not provided here. Cancer that recurs either locally at the original cancer site or regionally is assumed to have similar effects on the patient's functional and emotional state as the initial diagnosis. Recurrent cancer after an initial "curative therapy" may, however, have a greater emotional impact because it represents a failure to totally eradicate the tumour. If the cancer has metastasized to other parts of the body at recurrence, the diagnosis of recurrence is likely to have a far greater impact on the patient's psychological state, since metastatic disease is considered incurable. Some patients move between remission and relapse several times. This most typically occurs with metastatic breast cancer, but is becoming more common with other tumours for which there are moderately effective therapies.

Palliative and terminal care

When cancer has advanced to the point where it is not considered curable, the treatment approach is described as palliative. The objective of palliative care is to provide the best possible quality of life and to extend survival, if possible. This includes the use of any therapeutic option to relieve pain or discomfort, as well as the provision of psychological, social and spiritual support. Many patients experience a long period of palliative treatment during which their tumour is controlled (breast cancer being the best example); however, palliative care is defined here as the five months of life prior to the terminal care phase (the last month before death). The goal of terminal care is to provide supportive care when no active anti-cancer therapy is available or suitable.

Palliative care

Description	This health state is defined as the five months before the terminal care phase. Existential, physical, and psychological well-being is generally improved following admission to a palliative care unit. Patients may experience pain and fatigue of varying degrees while in palliative care, as well as the side effects of the administration of morphine (constipation, nausea, vomiting, sleep disturbances, mental clouding and confusion). Many express concern that they can no longer fulfill their roles in the family and cannot perform household duties. Sadness, grief, anxiety and depression are common, as well as feelings of isolation.
Classification	Core **3 3 4 3 2 4** Supplementary **3 1 1 1 3**

Terminal care

Description

The health state of patients in the last month of life is similar to that in the palliative care state, except for the severity of the functional limitations experienced. For example, many patients experience severe pain or discomfort during this phase. Generalized weakness and fatigue can make even simple acts, such as feeding oneself, difficult.

"The last weeks of life are especially dramatic, with increased dependency, weakness, confusion, and inability to manage simple functional and personal tasks such as bathing, walking and continence."[7]

Classification	Core	Supplementary
	4 4 4 4 4 4	3 1 1 1 4

References

1. De Vita VT Jr, Hellman S, Rosenberg, SA (eds) Cancer: Principles & Practice of Oncology. 4th Edition. Philadelphia (PA): J.B. Lippincott Company; 1993. p. 2449.

2. National Cancer Institute of Canada. Canadian Cancer Statistics 2002. Toronto, Canada, 2002.

3. De Vita VT Jr, Hellman S, Rosenberg, SA (eds) Cancer: Principles & Practice of Oncology. 4th Edition. Philadelphia (PA): J.B. Lippincott Company; 1993. p. 1075.

4. Burke MA, Lowrence W, Perczek R. Emotional and cognitive burden of prostate cancer. Urol Clin North Am. 2003; 30(2):295-304.

5. Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Incidence - SEER 12 Regs Public-Use, Nov 2002 Sub (1973-2000), National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2003, based on the November 2002 submission. using Software: Surveillance Research Program, National Cancer Institute SEER*Stat software (www.seer.cancer.gov/seerstat) version 5.0.17.

6. Simunovic M, Gagliardi A, McCready D, Coates A, Levine M, DePetrillo D. A snapshot of waiting times for cancer surgery provided by surgeons affiliated with regional cancer centres in Ontario. CMAJ 2001; 165(4): 421-5

7. De Vita VT Jr, Hellman S, Rosenberg, SA (eds) Cancer: Principles & Practice of Oncology. 4th Edition. Philadelphia (PA): J.B. Lippincott Company; 1993. p. 2503.

The following references were used as general sources to describe the cancers, their main symptoms and treatment courses:

Bast RC, Kufe DW, Donald W et al, (eds). Cancer Medicine. 5th Edition. B C Decker Inc; 2000.

De Vita VT Jr, Hellman S, Rosenberg, SA (eds) Cancer: Principles & Practice of Oncology. 4th Edition. Philadelphia (PA): J.B. Lippincott Company; 1993.

Unless otherwise specified, estimates of the number of new cancer cases and deaths were taken from:

National Cancer Institute of Canada. *Canadian Cancer Statistics 2002*. Toronto, Canada, 2002.

The following references were used for the health state descriptions:

[no author listed] Bladder cancer. Harv Mens Health Watch 2002;6(9):3-6.

Agrawal S, Benjamin IS. The patient with stomach cancer. Practitioner 2003; 247(1646):384-8, 390.

Ahles TA, Blanchard EB, Ruckdeschel JC. The multidimensional nature of cancer-related pain. Pain 1983; 17(3):277-288.

Ahles TA, Saykin AJ, Furstenberg CT, Cole B, Mott LA, Skalla K et al. Neuropsychologic impact of standard-dose systemic chemotherapy in long-term survivors of breast cancer and lymphoma. J Clin Oncol 2002; 20(2):485-493.

Aisner J. Management of advanced disseminated breast cancer. In: Moussa A, Schimpff S, Robson M, editors. Comprehensive Textbook of Oncology, Volume One. Baltimore: Williams and Wilkins, 1991; p. 836-844.

Andersen BL. Sexual functioning morbidity among cancer survivors: Current status and future research directions. Cancer 1985; 55(8):1835-1842.

Anderson H, Palmer MK. Measuring quality of life: impact of chemotherapy for advanced colorectal cancer. Experience from two recent large phase III trials. Br J Cancer 1998; 77 Suppl 2:9-14.:9-14.

Andrykowski MA, Curran SL, Lightner R. Off-treatment fatigue in breast cancer survivors: a controlled comparison. J Behav Med 1998; 21(1):1-18.

Badger TA, Braden CJ, Mishel MH. Depression burden, self-help interventions, and side effect experience in women receiving treatment for breast cancer. Oncol Nurs Forum 2001; 28(3):567-574.

Baird AD, Woolfenden KA, Desmond AD, Fordham MV, Parsons KF. Outcome and survival with nonsurgical management of renal cell carcinoma. BJU Int 2003; 91(7):600-602.

Barton-Burke M, Wilkes GM, Ingwersen KC. Cancer Chemotherapy: A Nursing Process Approach, Third Edition. Sudbury (MA): Jones and Bartlett Publishers; 2001.

Beach P, Siebereck B, Buderer NF, Ferner T. Relationship between fatigue and nutritional status in patients receiving radiation therapy to treat lung cancer. Oncol Nurs Forum 2001; 28(6):1027-1031.

Beckles MA, Spiro SG, Colice GL, Rudd RM. Initial evaluation of the patient with lung cancer: symptoms, signs, laboratory tests, and paraneoplastic syndromes. Chest 2003; 123(1 Suppl):97S-104S.

Berger AM, VonEssen S, Kuhn BR, Piper BF, Agrawal S, Lynch JC et al. Adherence, sleep, and fatigue outcomes after adjuvant breast cancer chemotherapy: results of a feasibility intervention study. Oncol Nurs Forum 2003; 30(3):513-522.

Bergman B, Sullivan M, Sorenson S. Quality of life during chemotherapy for small cell lung cancer. I. An evaluation with generic health measures. Acta Oncol 1991; 30(8):947-957.

Bergman B, Sullivan M, Sorenson S. Quality of life during chemotherapy for small cell lung cancer. II. A longitudinal study of the EORTC Core Quality of Life Questionnaire and comparison with the Sickness Impact Profile. Acta Oncol 1992; 31(1):19-28.

Bergman B, Aaronson NK, Ahmedzai S, Kaasa S, Sullivan M. The EORTC QLQ-LC13: a modular supplement to the EORTC Core Quality of Life Questionnaire (QLQ-C30) for use in lung cancer clinical trials. EORTC Study Group on Quality of Life. Eur J Cancer 1994; 30A(5):635-642.

Berkery R, Baltzer Cleri L, Skarin AT. Oncology Pocket Guide to Chemotherapy, Third Edition. St. Louis (MO): Mosby-Year Book Inc.; 1997.

Billings JA. Outpatient Management of Advanced Cancer: Symptom Control, Support, and Hospice-in-the-Home. Philadelphia (PA): JB Lippincott Company; 1985.

Bisson JI, Chubb HL, Bennett S, Mason M, Jones D, Kynaston H. The prevalence and predictors of psychological distress in patients with early localized prostate cancer. BJU Int 2002; 90(1):56-61.

Black PK, Hyde C. Parents with colorectal cancer: "What do I tell the children?". Br J Nurs 2002; 11(10):679-685.

Bliss JM, Robertson B, Selby PJ. The impact of nausea and vomiting upon quality of life measures. Br J Cancer Suppl 1992; 19:S14-22; discussion S23:S14-S22.

Bosompra K, Ashikaga T, O'Brien PJ, Nelson L, Skelly J. Swelling, numbness, pain, and their relationship to arm function among breast cancer survivors: a disablement process model perspective. Breast J 2002; 8(6):338-348.

Bowles MJ, Benjamin IS. ABC of the upper gastrointestinal tract: Cancer of the stomach and pancreas. BMJ 2001; 323(7326):1413-1416.

Broeckel JA, Jacobsen PB, Horton J, Balducci L, Lyman GH. Characteristics and correlates of fatigue after adjuvant chemotherapy for breast cancer. J Clin Oncol 1998; 16(5):1689-1696.

Bruera E, Russell N, Sweeney C, Fisch M, Palmer JL. Place of death and its predictors for local patients registered at a comprehensive cancer center. J Clin Oncol 2002; 20(8):2127-2133.

Bukberg J, Penman D, Holland JC. Depression in hospitalized cancer patients. Psychosom Med 1984; 46(3):199-212.

Bunn PAJ. Lung Cancer: current understanding of the biology, diagnosis, staging, and treatment. Bristol-Myers Oncology Division; 1991.

Burke MA, Lowrance W, Perczek R. Emotional and cognitive burden of prostate cancer. Urol Clin North Am 2003; 30(2):295-304.

Butler L, Downe-Wamboldt B, Marsh S, Bell D, Jarvi K. Quality of life post radical prostatectomy: a male perspective. Urol Nurs 2001; 21(4):283-288.

Calvo E, Cortes J, Gonzalez-Cao M, Rodriguez J, Aramendia JM, Fernandez-Hidalgo O et al. Combined irinotecan, oxaliplatin and 5-fluorouracil in patients with advanced colorectal cancer. a feasibility pilot study. Oncology 2002; 63(3):254-265.

Carlson K, Beck D. Urinary Bladder Cancer. Ostomy Quarterly 2002; 39(2):40-41.

Carlsson M, Hamrin E. Measurement of quality of life in women with breast cancer. Development of a Life Satisfaction Questionnaire (LSQ-32) and a comparison with the EORTC QLQ-C30. Qual Life Res 1996; 5(2):265-274.

Carmalt HL, Gillett DJ, Lin BP. Early gastric cancer. Aust N Z J Surg 1990; 60(11):865-869.

Carver CS, Pozo Kaderman C, Harris SD, Noriega V, Scheier MF, Robinson DS et al. Optimism versus pessimism predicts the quality of women's adjustment to early stage breast cancer. Cancer 1994; 73:1213-1220.

Cella D, Lai JS, Chang CH, Peterman A, Slavin M. Fatigue in cancer patients compared with fatigue in the general United States population. Cancer 2002; 94(2):528-538.

Cerny T, Gillessen S. Advances in the treatment of non-Hodgkin's lymphoma. Ann Oncol 2002; 13 Suppl 4:211-6.:211-216.

Chie WC, Huang CS, Chen JH, Chang KJ. Measurement of the quality of life during different clinical phases of breast cancer. J Formos Med Assoc 1999; 98(4):254-260.

Chirikos TN, Russell-Jacobs A, Jacobsen PB. Functional impairment and the economic consequences of female breast cancer. Women Health 2002; 36(1):1-20.

Ciaramella A, Poli P. Assessment of depression among cancer patients: the role of pain, cancer type and treatment. Psychooncology 2001; 10(2):156-165.

Clark JA, Wray N, Brody B, Ashton C, Giesler B, Watkins H. Dimensions of quality of life expressed by men treated for metastatic prostate cancer. Soc Sci Med 1997; 45(8):1299-1309.

Cleeland CS. Cancer-related symptoms. Semin Radiat Oncol 2000; 10(3):175-190.

Coates A, Gebski V, Bishop JF, Jeal PN, Woods RL, Snyder R et al. Improving the quality of life during chemotherapy for advanced breast cancer. A comparison of intermittent and continuous treatment strategies. N Engl J Med 1987; 317(24):1490-1495.

Cohen SJ, Pinover WH, Watson JC, Meropol NJ. Pancreatic cancer. Curr Treat Options Oncol 2000; 1(5):375-386.

Cohen SR, Leis A. What determines the quality of life of terminally ill cancer patients from their own perspective? J Palliat Care 2002; 18(1):48-58.

Conner-Spady B, Cumming C, Nabholtz JM, Jacobs P, Stewart D. Responsiveness of the EuroQol in breast cancer patients undergoing high dose chemotherapy. Qual Life Res 2001; 10(6):479-486.

Coveney E, Weltz CR, Greengrass R, Iglehart JD, Leight GS, Steele SM et al. Use of paravertebral block anesthesia in the surgical management of breast cancer: experience in 156 cases. Ann Surg 1998; 227(4):496-501.

Coward DD. Self-transcendence and emotional well-being in women with advanced breast cancer. Oncol Nurs Forum 1991; 18(5):857-863.

Crawford ED, Wood DP, Petrylak DP, Scott J, Coltman CA, Jr., Raghavan D. Southwest Oncology Group studies in bladder cancer. Cancer 2003; 97(8 Suppl):2099-2108.

Crookes PF. Gastric cancer. Clin Obstet Gynecol 2002; 45(3):892-903.

Daponte D, Robinson MR, Smith PH. Prognostic significance of the symptoms associated with prostatic carcinoma. Eur Urol 1983; 9(5):270-272.

de Haes JC, Curran D, Aaronson NK, Fentiman IS. Quality of life in breast cancer patients aged over 70 years, participating in the EORTC 10850 randomised clinical trial. Eur J Cancer 2003; 39(7):945-951.

DeCosse JJ, Tsioulias GJ, Jacobson JS. Colorectal cancer: detection, treatment, and rehabilitation. CA Cancer J Clin 1994; 44(1):27-42.

DeCosse JJ, Cennerazzo WJ. Quality-of-life management of patients with colorectal cancer. CA Cancer J Clin 1997; 47(4):198-206.

Diaz DL, Oteiza MF, Ciga MA, Aizcorbe M, Cobo F, Trujillo R. Impact of surgical procedure for gastric cancer on quality of life. Br J Surg 2003; 90(1):91-94.

DiPiro JT, Talbert RL, Yee GC, Matzke GR, Wells BG, Posey LM, eds. Pharmacotherapy: A Pathophysiological Approach, Fifth Edition. New York: McGraw-Hill Medical Publishing Division; 2002.

Dodd MJ, Miaskowski C, Paul SM. Symptom clusters and their effect on the functional status of patients with cancer. Oncol Nurs Forum 2001; 28(3):465-470.

Dooley WC. Ambulatory breast cancer surgery. Ann Surg Oncol 2000; 7(3):174-175.

Eton DT, Lepore SJ. Prostate cancer and health-related quality of life: a review of the literature. Psychooncology 2002; 11(4):307-326.

Fernandez C, Rosell R, Abad-Esteve A, Monras P, Moreno I, Serichol M et al. Quality of life during chemotherapy in non-small cell lung cancer patients. Acta Oncol 1989; 28(1):29-33.

Ferrell BR, Grant M, Funk B, Otis-Green S, Garcia N. Quality of life in breast cancer. Part II: Psychological and spiritual well-being. Cancer Nurs 1998; 21(1):1-9.

Fielding JW, Ellis DJ, Jones BG, Paterson J, Powell DJ, Waterhouse JA et al. Natural history of "early" gastric cancer: results of a 10-year regional survey. Br Med J 1980; 281(6246):965-967.

Fischer DS, Marsh JC, eds. Cancer Therapy. Boston (MA): GK Hall Medical Publishers; 1982.

Forsberg C, Bjorvell H, Cedermark B. Well-being and its relation to coping ability in patients with colorectal and gastric cancer before and after surgery. Scand J Caring Sci 1996; 10(1):35-44.

Freeman JR, Broshek DK. Assessing cognitive dysfunction in breast cancer: what are the tools? Clin Breast Cancer 2002; 3 Suppl 3:S91-9.:S91-S99.

Fujii Y, Tanaka H, Kawasaki T. Preoperative oral granisetron for the prevention of postoperative nausea and vomiting after breast surgery. Eur J Surg 2001; 167(3):184-187.

Fujisawa M, Isotani S, Gotoh A, Okada H, Arakawa S, Kamidono S. Health-related quality of life with orthotopic neobladder versus ileal conduit according to the SF-36 survey. Urology 2000; 55(6):862-865.

Ganz PA, Coscarelli A, Fred C, Kahn B, Polinsky ML, Petersen L. Breast cancer survivors: psychosocial concerns and quality of life. Breast Cancer Res Treat 1996; 38(2):183-199.

Ganz PA, Rowland JH, Desmond K, Meyerowitz BE, Wyatt GE. Life after breast cancer: understanding women's health-related quality of life and sexual functioning. J Clin Oncol 1998; 16(2):501-514.

Ganz PA, Desmond KA, Belin TR, Meyerowitz BE, Rowland JH. Predictors of sexual health in women after a breast cancer diagnosis. J Clin Oncol 1999; 17(8):2371-2380.

Garnick MB. Prostate cancer: screening, diagnosis, and management. Ann Intern Med 1993; 118(10):804-818.

Genre D, Protiere C, Macquart-Moulin G, Gravis G, Camerlo J, Alzieu C et al. Quality of life of breast cancer patients receiving high-dose-intensity chemotherapy: impact of length of cycles. Support Care Cancer 2002; 10(3):222-230.

Giesler RB, Miles BJ, Cowen ME, Kattan MW. Assessing quality of life in men with clinically localized prostate cancer: development of a new instrument for use in multiple settings. Qual Life Res 2000; 9(6):645-665.

Glimelius B, Graf W, Hoffman K, Pahlman L, Sjoden PO, Wennberg A. General condition of asymptomatic patients with advanced colorectal cancer receiving palliative chemotherapy. A longitudinal study. Acta Oncol 1992; 31(6):645-651.

Graydon JE. Women with breast cancer: their quality of life following a course of radiation therapy. J Adv Nurs 1994; 19(4):617-622.

Greenwald HP, Bonica JJ, Bergner M. The prevalence of pain in four cancers. Cancer 1987; 60(10):2563-2569.

Greimel E, Thiel I, Peintinger F, Cegna: I, Pongratz E. Prospective assessment of quality of life of female cancer patients. Gynecol Oncol 2002; 85(1):140-147.

Guren MG, Dueland S, Skovlund E, Fossa SD, Poulsen JP, Tveit KM. Quality of life during radiotherapy for rectal cancer. Eur J Cancer 2003; 39(5):587-594.

Handy JR, Jr., Asaph JW, Skokan L, Reed CE, Koh S, Brooks G et al. What happens to patients undergoing lung cancer surgery? Outcomes and quality of life before and after surgery. Chest 2002; 122(1):21-30.

Hann DM, Jacobsen PB, Azzarello LM, Martin SC, Curran SL, Fields KK et al. Measurement of fatigue in cancer patients: development and validation of the Fatigue Symptom Inventory. Qual Life Res 1998; 7(4):301-310.

Hardt J, Filipas D, Hohenfellner R, Egle UT. Quality of life in patients with bladder carcinoma after cystectomy: first results of a prospective study. Qual Life Res 2000; 9(1):1-12.

Harnois C, Malenfant M, Dupont A, Labrie F. Ocular toxicity of Anandron in patients treated for prostatic cancer. Br J Ophthalmol 1986; 70(6):471-473.

Hart S, Skinner EC, Meyerowitz BE, Boyd S, Lieskovsky G, Skinner DG. Quality of life after radical cystectomy for bladder cancer in patients with an ileal conduit, cutaneous or urethral kock pouch. J Urol 1999; 162(1):77-81.

Henningsohn L, Wijkstrom H, Steven K, Pedersen J, Ahlstrand C, Aus G et al. Relative importance of sources of symptom-induced distress in urinary bladder cancer survivors. Eur Urol 2003; 43(6):651-662.

Henningsohn L, Wijkstrom H, Pedersen J, Ahlstrand C, Aus G, Bergmark K et al. Time after surgery, symptoms and well-being in survivors of urinary bladder cancer. BJU Int 2003; 91(4):325-330.

Henry-Amar M. Hodgkin's disease. Treatment sequelae and quality of life. Baillieres Clin Haematol 1996; 9(3):595-618.

Higano CS. Side effects of androgen deprivation therapy: monitoring and minimizing toxicity. Urology 2003; 61(2 Suppl 1):32-38.

Higginson IJ, Hearn J. A multicenter evaluation of cancer pain control by palliative care teams. J Pain Symptom Manage 1997; 14(1):29-35.

Hoffman PC, Mauer AM, Vokes EE. Lung cancer. Lancet 2000; 355(9202):479-485.

Hollen PJ, Gralla RJ, Kris MG, Potanovich LM. Quality of life assessment in individuals with lung cancer: testing the Lung Cancer Symptom Scale (LCSS). Eur J Cancer 1993; 29A Suppl 1:S51-8.:S51-S58.

Hollen PJ, Gralla RJ, Kris MG, Eberly SW, Cox C. Normative data and trends in quality of life from the Lung Cancer Symptom Scale (LCSS). Support Care Cancer 1999; 7(3):140-148.

Holzner B, Kemmler G, Sperner-Unterweger B, Kopp M, Dunser M, Margreiter R et al. Quality of life measurement in oncology—a matter of the assessment instrument? Eur J Cancer 2001; 37(18):2349-2356.

Holzner B, Kemmler G, Kopp M, Moschen R, Schweigkofler H, Dunser M et al. Quality of life in breast cancer patients—not enough attention for long-term survivors? Psychosomatics 2001; 42(2):117-123.

Hurny C, Bernhard J, Joss R, Schatzmann E, Cavalli F, Brunner K et al. "Fatigue and malaise" as a quality-of-life indicator in small-cell lung cancer patients. The Swiss Group for Clinical Cancer Research (SAKK). Support Care Cancer 1993; 1(6):316-320.

Janni W, Rjosk D, Dimpfl TH, Haertl K, Strobl B, Hepp F et al. Quality of life influenced by primary surgical treatment for stage I-III breast cancer-long-term follow-up of a matched-pair analysis. Ann Surg Oncol 2001; 8(6):542-548.

Kaasa S, Mastekaasa A, Thorud E. Toxicity, physical function and everyday activity reported by patients with inoperable non-small cell lung cancer in a randomized trial (chemotherapy versus radiotherapy). Acta Oncol 1988; 27(4):343-349

Kalser MH, Barkin J, MacIntyre JM. Pancreatic cancer. Assessment of prognosis by clinical presentation. Cancer 1985; 56(2):397-402.

Kemp C. Terminal Illness: A Guide to Nursing Care, Second Edition. Philadelphia (PA): Lippincott, Williams, and Wilson; 1999.

Kettelman KP. Why give more morphine to a dying patient? Nursing 1999; 29(11):54-55.

Kirsh KL, Passik S, Holtsclaw E, Donaghy K, Theobald D. I get tired for no reason: a single item screening for cancer-related fatigue. J Pain Symptom Manage 2001; 22(5):931-937.

Kissane DW, Clarke DM, Ikin J, Bloch S, Smith GC, Vitetta L et al. Psychological morbidity and quality of life in Australian women with early-stage breast cancer: a cross-sectional survey. Med J Aust 1998; 169(4):192-196.

Knobf MT. Symptoms and rehabilitation needs of patients with early stage breast cancer during primary therapy. Cancer 1990; 66:1392-1401.

Koopman C, Nouriani B, Erickson V, Anupindi R, Butler LD, Bachmann MH et al. Sleep disturbances in women with metastatic breast cancer. Breast J 2002; 8(6):362-370.

Koukouras D, Spiliotis J, Scopa CD, Dragotis K, Kalfarentzos F, Tzoracoleftherakis E et al. Radical consequence in the sexuality of male patients operated for colorectal carcinoma. Eur J Surg Oncol 1991; 17(3):285-288.

Koyi H, Hillerdal G, Branden E. A prospective study of a total material of lung cancer from a county in Sweden 1997-1999: gender, symptoms, type, stage, and smoking habits. Lung Cancer 2002; 36(1):9-14.

Kuo TT, Ma FC. Symptom distresses and coping strategies in patients with non-small cell lung cancer. Cancer Nurs 2002; 25(4):309-317.

Kyle SM, Isbister WH, Yeong ML. Presentation, duration of symptoms and staging of colorectal carcinoma. Aust N Z J Surg 1991; 61(2):137-140.

Langendijk JA, Aaronson NK, ten Velde GP, de Jong JM, Muller MJ, Wouters EF. Pretreatment quality of life of inoperable non-small cell lung cancer patients referred for primary radiotherapy. Acta Oncol 2000; 39(8):949-958.

Langendijk JA, Aaronson NK, de Jong JM, ten Velde GP, Muller MJ, Slotman BJ et al. Quality of life after curative radiotherapy in Stage I non-small-cell lung cancer. Int J Radiat Oncol Biol Phys 2002; 53(4):847-853.

Lee F, Patel HR. Kidney cancer: current management guidelines. Hosp Med 2002; 63(4):214-217.

Lee PY, Fletcher WS, Sullivan ES, Vetto JT. Colorectal cancer in young patients: characteristics and outcome. Am Surg 1994; 60(8):607-612.

Leonard RCF, Rodger A, Dixon JM. Metastatic Breast Cancer. BMJ 1994; 309:1501-1504.

Lepor H, Nieder AM, Fraiman MC. Early removal of urinary catheter after radical retropubic prostatectomy is both feasible and desirable. Urology 2001; 58(3):425-429.

Lilleby W, Fossa SD, Wachre HR, Olsen DR. Long-term morbidity and quality of life in patients with localized prostate cancer undergoing definitive radiotherapy or radical prostatectomy. Int J Radiat Oncol Biol Phys 1999; 43(4):735-743.

Litwin MS, Hays RD, Fink A, Ganz PA, Leake B, Brook RH. The UCLA Prostate Cancer Index: development, reliability, and validity of a health-related quality of life measure. Med Care 1998; 36(7):1002-1012.

Long DS. How breast cancer patients choose a treatment method. Radiol Technol 1993; 65:30-33.

Lubbe AS, Krischke NR, Dimeo F, Forkel S, Petermann F. Health-related quality of life and pulmonary function in lung cancer patients undergoing medical rehabilitation treatment. Wien Med Wochenschr 2001; 151(1-2):29-34.

Luoma ML, Hakamies-Blomqvist L, Sjostrom J, Mouridsen H, Pluzanska A, Malmstrom P et al. Physical performance, toxicity, and quality of life as assessed by the physician and the patient. Acta Oncol 2002; 41(1):44-49.

Lutz S, Norrell R, Bertucio C, Kachnic L, Johnson C, Arthur D et al. Symptom frequency and severity in patients with metastatic or locally recurrent lung cancer: a prospective study using the Lung Cancer Symptom Scale in a community hospital. J Palliat Med 2001; 4(2):157-165.

Lynch M, Abrahm J. Ensuring a good death. Cancer Pract 2002; 10 Suppl 1:S33-8.:S33-S38.

Maasilta PK, Rautonen JK, Mattson MT, Mattson KV. Quality of life assessment during chemotherapy for non-small cell lung cancer. Eur J Cancer 1990; 26(6):706-708.

Magee CJ, Shekoush A, Ghaneh P, Neoptolemos JP. Update on pancreatic cancer. Hosp Med 2002; 63(4):200-206.

Manabe T, Miyashita T, Ohshio G, Nonaka A, Suzuki T, Endo K et al. Small carcinoma of the pancreas. Clinical and pathologic evaluation of 17 patients. Cancer 1988; 62(1):135-141.

Marineo G. Untreatable pain resulting from abdominal cancer: new hope from biophysics? JOP 2003; 4(1):1-10.

Mathews A, Ridgeway V, Warren R, Britton P. Predicting worry following a diagnosis of breast cancer. Psychooncology 2002; 11(5):415-418.

Matsuda T, Aptel I, Exbrayat C, Grosclaude P. Determinants of quality of life of bladder cancer survivors five years after treatment in France. Int J Urol 2003; 10(8):423-429.

Maughan TS, James RD, Kerr DJ, Ledermann JA, McArdle C, Seymour MT et al. Comparison of survival, palliation, and quality of life with three chemotherapy regimens in metastatic colorectal cancer: a multicentre randomised trial. Lancet 2002; 359(9317):1555-1563.

McConnell EA. Loosening the grip of intestinal obstructions. Nursing 1994; 24(3):34-41.

McElwain TJ. Hodgkin's and non-Hodgkin's lymphomas. Br J Hosp Med 1984; 31(1):10-19.

McLachlan SA, Devins GM, Goodwin PJ. Validation of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (QLQ-C30) as a measure of psychosocial function in breast cancer patients. Eur J Cancer 1998; 34(4):510-517.

Mendoza TR, Wang XS, Cleeland CS, Morrissey M, Johnson BA, Wendt JK et al. The rapid assessment of fatigue severity in cancer patients: use of the Brief Fatigue Inventory. Cancer 1999; 85(5):1186-1196.

Meyerowitz BE, Desmond KA, Rowland JH, Wyatt GE, Ganz PA. Sexuality following breast cancer. J Sex Marital Ther 1999; 25(3):237-250.

Michael M, Moore MJ. Assessing the impact of chemotherapy on tumor-related symptoms in advanced colorectal cancer. Oncology (Huntingt) 1998; 12(8 Suppl 6):121-128.

Milowsky MI, Nanus DM. Advanced renal cell carcinoma. Curr Treat Options Oncol 2001; 2(5):437-445.

Minardi AJ, Jr., Sittig KM, Zibari GB, McDonald JC. Colorectal cancer in the young patient. Am Surg 1998; 64(9):849-853.

Mock V, Atkinson A, Barsevick A, Cella D, Cimprich B, Cleeland C et al. NCCN Practice Guidelines for Cancer-Related Fatigue. Oncology (Huntingt) 2000; 14(11A):151-161.

Monga U, Kerrigan AJ, Thornby J, Monga TN. Prospective study of fatigue in localized prostate cancer patients undergoing radiotherapy. Radiat Oncol Investig 1999; 7(3):178-185.

Montazeri A, Milroy R, Hole D, McEwen J, Gillis CR. Quality of life in lung cancer patients: as an important prognostic factor. Lung Cancer 2001; 31(2-3):233-240.

Mosconi P, Apolone G, Barni S, Secondino S, Sbanotto A, Filiberti A. Quality of life in breast and colon cancer long-term survivors: an assessment with the EORTC QLQ-C30 and SF-36 questionnaires. Tumori 2002; 88(2):110-116.

Myrdal G, Valtysdottir S, Lambe M, Stahle E. Quality of life following lung cancer surgery. Thorax 2003; 58(3):194-197.

Mystakidou K, Parpa E, Tsilika E, Kalaidopoulou O, Vlahos L. The families evaluation on management, care and disclosure for terminal stage cancer patients. BMC Palliat Care 2002; 1(1):3.

Newport DJ, Nemeroff CB. Assessment and treatment of depression in the cancer patient. J Psychosom Res 1998; 45(3):215-237.

Nissen MJ, Swenson KK, Ritz LJ, Farrell JB, Sladek ML, Lally RM. Quality of life after breast carcinoma surgery: a comparison of three surgical procedures. Cancer 2001; 91(7):1238-1246.

O'Driscoll M, Corner J, Bailey C. The experience of breathlessness in lung cancer. Eur J Cancer Care (Engl) 1999; 8(1):37-43.

Okuyama T, Akechi T, Kugaya A, Okamura H, Imoto S, Nakano T et al. Factors correlated with fatigue in disease-free breast cancer patients: application of the Cancer Fatigue Scale. Support Care Cancer 2000; 8(3):215-222.

Okuyama T, Tanaka K, Akechi T, Kugaya A, Okamura H, Nishiwaki Y et al. Fatigue in ambulatory patients with advanced lung cancer: prevalence, correlated factors, and screening. J Pain Symptom Manage 2001; 22(1):554-564.

Olson K, Tom B, Hewitt J, Whittingham J, Buchanan L, Ganton G. Evolving routines: preventing fatigue associated with lung and colorectal cancer. Qual Health Res 2002; 12(5):655-670.

Osoba D, Zee B, Pater J, Warr D, Kaizer L, Latreille J. Psychometric properties and responsiveness of the EORTC quality of Life Questionnaire (QLQ-C30) in patients with breast, ovarian and lung cancer. Qual Life Res 1994; 3(5):353-364.

Osoba D, Tannock IF, Ernst DS, Neville AJ. Health-related quality of life in men with metastatic prostate cancer treated with prednisone alone or mitoxantrone and prednisone. J Clin Oncol 1999; 17(6):1654-1663.

Pace KT, Dyer SJ, Stewart RJ, Honey RJ, Poulin EC, Schlachta CM et al. Health-related quality of life after laparoscopic and open nephrectomy. Surg Endosc 2003; 17(1):143-152.

Pandey M, Singh SP, Behere PB, Roy SK, Singh S, Shukla VK. Quality of life in patients with early and advanced carcinoma of the breast. Eur J Surg Oncol 2000; 26(1):20-24.

Pargeon KL, Hailey BJ. Barriers to effective cancer pain management: a review of the literature. J Pain Symptom Manage 1999; 18(5):358-368.

Parramore JB, Wei JP, Yeh KA. Colorectal cancer in patients under forty: presentation and outcome. Am Surg 1998; 64(6):563-567.

Pashos CL, Botteman MF, Laskin BL, Redaelli A. Bladder cancer: epidemiology, diagnosis, and management. Cancer Pract 2002; 10(6):311-322.

Pasini F, Pelosi G, Valduga F, Durante E, de Manzoni G, Zaninelli M et al. Late events and clinical prognostic factors in stage I non small cell lung cancer. Lung Cancer 2002; 37(2):171-177.

Passik SD, Dugan W, McDonald MV, Rosenfeld B, Theobald DE, Edgerton S. Oncologists' recognition of depression in their patients with cancer. J Clin Oncol 1998; 16(4):1594-1600.

Penson DF. Quality of life following prostate cancer treatments. Curr Urol Rep 2000; 1(1):71-77.

Penson DF, Litwin MS. The physical burden of prostate cancer. Urol Clin North Am 2003; 30(2):305-313.

Persson L, Hallberg IR, Ohlsson O. Survivors of acute leukaemia and highly malignant lymphoma—retrospective views of daily life problems during treatment and when in remission. J Adv Nurs 1997; 25(1):68-78.

Pierce SM, Harris JR. Radiation therapy to the breast: practical aspects. J Am Med Wom Assoc 1992; 47:174-7, 187.

Plataniotis GA, Kouvaris JR, Dardoufas C, Kouloulias V, Theofanopoulou MA, Vlahos L. A short radiotherapy course for locally advanced non-small cell lung cancer (NSCLC): effective palliation and patients' convenience. Lung Cancer 2002; 35(2):203-207.

Polinsky ML. Functional status of long-term breast cancer survivors: demonstrating chronicity. Health Soc Work 1994; 19(3):165-173.

Potosky AL, Legler J, Albertsen PC, Stanford JL, Gilliland FD, Hamilton AS et al. Health outcomes after prostatectomy or radiotherapy for prostate cancer: results from the Prostate Cancer Outcomes Study. J Natl Cancer Inst 2000; 92(19):1582-1592.

Prucha EJ. Cancer Sourcebook. Detroit (MI): Omnigraphics Inc.; 2000.

Purushotham AD, McLatchie E, Young D, George WD, Stallard S, Doughty J et al. Randomized clinical trial of no wound drains and early discharge in the treatment of women with breast cancer. Br J Surg 2002; 89(3):286-292.

Quesnel C, Savard J, Simard S, Ivers H, Morin CM. Efficacy of cognitive-behavioral therapy for insomnia in women treated for nonmetastatic breast cancer. J Consult Clin Psychol 2003; 71(1):189-200.

Radice D, Redaelli A. Breast cancer management: quality-of-life and cost considerations. Pharmacoeconomics 2003; 21(6):383-396.

Richer MC, Ezer H. Living in it, living with it, and moving on: dimensions of meaning during chemotherapy. Oncol Nurs Forum 2002; 29(1):113-119.

Rietman JS, Dijkstra PU, Hoekstra HJ, Eisma WH, Szabo BG, Groothoff JW et al. Late morbidity after treatment of breast cancer in relation to daily activities and quality of life: a systematic review. Eur J Surg Oncol 2003; 29(3):229-238.

Rothchild E. Family dynamics in end-of-life treatment decisions. Gen Hosp Psychiatry 1994; 16(4):251-258.

Sarna L, Brecht ML. Dimensions of symptom distress in women with advanced lung cancer: a factor analysis. Heart Lung 1997; 26(1):23-30.

Sarna L, Padilla G, Holmes C, Tashkin D, Brecht ML, Evangelista L. Quality of life of long-term survivors of non-small-cell lung cancer. J Clin Oncol 2002; 20(13):2920-2929.

Schag CA, Ganz PA, Polinsky ML, Fred C, Hirji K, Petersen L. Characteristics of women at risk for psychosocial distress in the year after breast cancer. J Clin Oncol 1993; 11(4):783-793.

Schagen SB, van Dam FS, Muller MJ, Boogerd W, Lindeboom J, Bruning PF. Cognitive deficits after postoperative adjuvant chemotherapy for breast carcinoma. Cancer 1999; 85(3):640-650.

Schmidt JD. The patient, disease status, and treatment options for prostate cancer: stages D1 and D2. Prostate 1983; 4(5):493-501.

Schow DA, Renfer LG, Rozanski TA, Thompson IM. Prevalence of hot flushes during and after neoadjuvant hormonal therapy for localized prostate cancer. South Med J 1998; 91(9):855-857.

Scieszka M, Zielinski M, Machalski M, Herman ZS. Quality of life in cancer patients treated by chemotherapy. Neoplasma 2000; 47(6):396-399.

Seidman AD. Monotherapy options in the management of metastatic breast cancer. Semin Oncol 2003; 30(2 Suppl 3):6-10.

Sestini AS, Pakenham KI. Cancer of the prostate: A biopsychosocial review. Journal of Psychosocial Oncology 2000; 18(1):17-38.

Shahrudin MD, Noori SM. Cancer of the colon and rectum in the first three decades of life. Hepatogastroenterology 1997; 44(14):441-444.

Sousa-Escandon A, Vazquez S, Quintero-Aldana G, Picallo JA, Neira J, Garcia-Novio F et al. Neo-adjuvant treatment of infiltrating transitional-cell carcinoma of the bladder with paclitaxel and cisplatin: a phase II trial. Int J Urol 2002; 9(3):162-166.

Spiegel D. Cancer and depression. Br J Psychiatry Suppl 1996;(30):109-116.

Sprangers MA, Taal BG, Aaronson NK, te Velde A. Quality of life in colorectal cancer. Stoma vs. nonstoma patients. Dis Colon Rectum 1995; 38(4):361-369.

Sridhar KS, Bounassi MJ, Raub W, Jr., Richman SP. Clinical features of adenosquamous lung carcinoma in 127 patients. Am Rev Respir Dis 1990; 142(1):19-23.

Stein W, Farina A, Gaffney K, Lundeen C, Wagner K, Wachtel T. Characteristics of colon cancer at time of presentation. Fam Pract Res J 1993; 13(4):355-363.

Stone P, Hardy J, Huddart R, A'Hern R, Richards M. Fatigue in patients with prostate cancer receiving hormone therapy. Eur J Cancer 2000; 36(9):1134-1141.

Stone P, Richards M, A'Hern R, Hardy J. Fatigue in patients with cancers of the breast or prostate undergoing radical radiotherapy. J Pain Symptom Manage 2001; 22(6):1007-1015.

Stubbs RS, Long MG. Symptom duration and pathologic staging of colorectal cancer. Eur J Surg Oncol 1986; 12(2):127-130.

Sullivan BA, McKinnis R, Laufman LR. Quality of life in patients with metastatic colorectal cancer receiving chemotherapy: a randomized, double-blind trial comparing 5-FU versus 5-FU with leucovorin. Pharmacotherapy 1995; 15(5):600-607.

Svedlund J, Sullivan M, Sjodin I, Liedman B, Lundell L. Quality of life in gastric cancer prior to gastrectomy. Qual Life Res 1996; 5(2):255-264.

Tanaka K, Akechi T, Okuyama T, Nishiwaki Y, Uchitomi Y. Impact of dyspnea, pain, and fatigue on daily life activities in ambulatory patients with advanced lung cancer. J Pain Symptom Manage 2002; 23(5):417-423.

Tanaka K, Akechi T, Okuyama T, Nishiwaki Y, Uchitomi Y. Factors correlated with dyspnea in advanced lung cancer patients: organic causes and what else? J Pain Symptom Manage 2002; 23(6):490-500.

Tanaka K, Akechi T, Okuyama T, Nishiwaki Y, Uchitomi Y. Prevalence and screening of dyspnea interfering with daily life activities in ambulatory patients with advanced lung cancer. J Pain Symptom Manage 2002; 23(6):484-489.

Theodossiou C, Schwarzenberger P. Non-Hodgkin's lymphomas. Clin Obstet Gynecol 2002; 45(3):820-829.

Thybusch-Bernhardt A, Schmidt C, Kuchler T, Schmid A, Henne-Bruns D, Kremer B. Quality of life following radical surgical treatment of gastric carcinoma. World J Surg 1999; 23(5):503-508.

Trachtenberg J. Innovative approaches to the hormonal treatment of advanced prostate cancer. Eur Urol 1997; 32 Suppl 3:78-80.

Trippoli S, Vaiani M, Lucioni C, Messori A. Quality of life and utility in patients with non-small cell lung cancer. Quality-of-life Study Group of the Master 2 Project in Pharmacoeconomics. Pharmacoeconomics 2001; 19(8):855-863.

Vainio A, Auvinen A. Prevalence of symptoms among patients with advanced cancer: an international collaborative study. Symptom Prevalence Group. J Pain Symptom Manage 1996; 12(1):3-10.

Valente SM, Saunders JM, Cohen MZ. Evaluating depression among patients with cancer. Cancer Pract 1994; 2(1):65-71.

Vinokur AD, Threatt BA, Caplan RD, Zimmerman BL. Physical and psychosocial functioning and adjustment to breast cancer. Long-term follow-up of a screening population. Cancer 1989; 63(2):394-405.

Wai CY, Miller DS. Urinary bladder cancer. Clin Obstet Gynecol 2002; 45(3):844-854.

Waldman AR. Understanding non-Hodgkin's lymphomas. Clin J Oncol Nurs 2003; 7(1):93-96.

Wang H, Huang E, Dale W, Campbell T, Ignacio L, Kopnick M et al. Self-assessed health-related quality of life in men who have completed radiotherapy for prostate cancer: instrument validation and its relation to patient-assessed bother of symptoms. Int J Cancer 2000; 90(3):163-172.

Wayne MS, Cath A, Pamies RJ. Colorectal cancer. A practical review for the primary care physician. Arch Fam Med 1995; 4(4):357-366.

Webster K, Cella D. Quality of life in patients with low-grade non-Hodgkin's lymphoma. Oncology (Huntingt) 1998; 12(5):697-714.

Weiss SC, Emanuel LL, Fairclough DL, Emanuel EJ. Understanding the experience of pain in terminally ill patients. Lancet 2001; 357(9265):1311-1315.

Whelan TJ, Levine M, Julian J, Kirkbride P, Skingley P. The effects of radiation therapy on quality of life of women with breast carcinoma: results of a randomized trial. Ontario Clinical Oncology Group. Cancer 2000; 88(10):2260-2266.

Winningham ML, Nail LM, Burke MB, Brophy L, Cimprich B, Jones LS et al. Fatigue and the cancer experience: the state of the knowledge. Oncol Nurs Forum 1994; 21(1):23-36.

Wolberg WH, Romsaas EP, Tanner MA, Malec JF. Psychosexual adaptation to breast cancer surgery. Cancer 1989; 63(8):1645-1655.

Wong K, Henderson IC. Management of metastatic breast cancer. World J Surg 1994; 18(1):98-111.

The following websites were also consulted:

American Cancer Society
http://www.cancer.org

BC Cancer Agency
http://www.bccancer.bc.ca

Cancer Care Ontario
http://www.cancercare.on.ca

Johns Hopkins
http://www.hopkinsmedicine.org

Mayo Clinic
http://www.mayoclinic.com

Medicine Online
http://www.meds.com

National Cancer Institute
http://www.nci.nih.gov

National Library of Medicine
http://www.nlm.nih.gov